Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-IDD). A qualitative exploration of feasibility and acceptability

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Thesis declaration form

UCL Doctorate in Clinical Psychology Thesis declaration form I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part 1: This section will report the findings of a systematic review of positive psychology and mental health outcome measures, for individuals with intellectual disabilities (ID) and dementia. A systematic search identified seven positive psychology and four mental health outcome measures across twelve studies. The review identified two potentially suitable quality of life measures, the QOMID and the QUALID. All other outcome measures failed to report on various psychometric properties, specifically for use with people who have dementia and ID. Developing or adapting outcome measures are discussed as key for providing suitable psychosocial interventions for this population.

Part 2: This section details the qualitative arm of an acceptability and feasibility trial for group-based Cognitive Stimulation Therapy (CST) with people who have dementia and ID (CST-IDD). Twenty qualitative interviews were carried out including five group participants (individuals with ID and dementia), nine group facilitators and six carers of people who attended the group. Qualitative analyses found that the acceptability and feasibility of CST-IDD for this population was intertwined, where improving acceptability (how the intervention was received) with a specific need for certain conditions, reduced overall feasibility (the practicality and possibility of running CST-IDD groups). Recommendations for future research and implications are discussed in detail.

Part 3: The first part of the critical appraisal will discuss further considerations in running a trial for CST-IDD with people who have ID and dementia. The second part will expand on the brief reflexivity statement in part two, considering the impact of the researcher’s identity on the various qualitative processes. The final part will reflect on the researcher’s experiences of joining a large scale NIHR funded trial.

Part two was a joint project with a previous trainee psychologist and part of a larger acceptability and feasibility trial, further details of contributions in Appendix M.

Impact Statement

People with ID have endured ill treatment at the hands of systems that are meant to support them in living a life full of meaning and purpose. Historical inequalities and harm towards people with ID still demonstrate a pervasive impact today. For example, people with ID are still more likely to die from avoidable causes compared to those without ID. This health inequality may be explained by a lack of adequate resources for the provision of high-quality learning disability services and little availability of good quality research to support care initiatives.

Cognitive Stimulation Therapy (CST) is a well-known group-based psychosocial intervention for dementia, recommended by NICE guidelines. People with ID are at a greater risk of developing dementia. However, there is only one existing psychosocial intervention trial for an individualised version of CST for people with ID, despite this increased risk. Therefore, part two of the thesis aimed to synthesise the qualitative experiences of participating in, facilitating and providing care for people with ID and dementia within an acceptability and feasibility trial for group CST. Including the views of the individual with ID and dementia was important and found that their ability to engage with the research process was dependent on having adequate supports in place. Within research, people with ID are often wrongly deemed unsuitable research ‘participants’ and research is often conducted with the system around the person.

The overall finding highlighted that people with ID and dementia can engage in and benefit from a psychosocial intervention with a consideration and implementation of relevant adaptations. However, the limitations in resources (often noted within services for people with ID) from practical arrangements to staff shortages were noted as key barriers.

The systematic review was driven by the difficulties in identifying suitable outcome measures for the acceptability and feasibility trial described in part two. The domains that are attended to in research are often those related to providing care (e.g. cognition, activities of daily living, behaviour) or areas of difficulty rather than domains which indicate psychosocial ‘thriving’ (e.g. quality of life, well-being, goal attainment). The lack of validated outcome measures highlights a key flaw with developing interventions aimed at improving psychological wellbeing for people with ID, as their personal experiences are not being captured within the research. The current systematic review found one quality of life outcome measure that has been developed and validated for use with people who have dementia and ID. Based on this finding, there is a need to validate or develop further outcome measures within positive psychology and mental health domains for people with ID and dementia.

This thesis aims to add to the growing research for people with ID and the continued emphasis that they deserve to live rich, fulfilling lives with the required supports to enable them to do so. This thesis also highlights the extent of support required to provide high quality services for people with ID. This includes adequate funding for services that support people with ID in order to ensure that their care is equitable.

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PART 1: SYSTEMATIC REVIEW

Psychometric properties of positive psychology and mental health outcome measures for individuals with Intellectual Disabilities (ID) and dementia: a systematic review

Abstract

Introduction: National initiatives have emphasised a need to promote person-centred care for people with ID, which should include seeking to support and improve their subjective experiences of life (also known as ‘positive psychology’) and overall mental health. However, there is little emphasis on person-centred outcomes for people with dementia and ID, with measures that are often completed by carers without a consideration of the subjective experiences of the person with ID and dementia. Outcome measures relating to life satisfaction, quality of life and related outcomes alongside mental health outcomes are limited for individuals with ID and dementia. In the context of national strategy (Department of Health and Social Care 2001; 2010) to improve the development of person-centred care initiatives for people with ID, given their increased risk of developing dementia, there is a need for suitable measures that relate to person-centred outcomes. The current review aimed to identify and methodologically appraise existing positive psychology and mental health outcome measures for people with ID and dementia. **Method:** A systematic review was carried out by searching three databases (MEDLINE, PsychInfo and Web of Science) by title and abstract. Studies were screened out by title, abstract and full text. The COSMIN risk of bias checklist was used to assess methodological quality. **Results:** Seven ‘positive psychology’ outcome measures were identified, of which six measured ‘quality of life’ and one measured ‘goal attainment’. Four mental health outcome measures were identified of which two measured ‘anxiety and depression’, and two measured general mental health difficulties. A total of twelve studies were suitable for inclusion. All included studies were either ‘inadequate’ in overall methodological quality and/or did not include more than two (out of ten) psychometric properties from the checklist. The methodological quality assessment combined with a narrative synthesis found two suitable positive psychology measure, the QOMID, that was developed for use with people who have ID and dementia, and the QUALID, not developed for use with this population, despite an overall ‘inadequate’ quality rating for both. All other outcome measures either appeared unsuitable for use with people with ID and dementia or required further high-quality research to determine suitability. **Discussion:** Limitations of the current review and implications for future research are discussed.

Introduction

Individuals with Intellectual Disabilities (ID) are at increased risk of developing dementia compared to the general population (Strydom et al., 2009; Lott & Head, 2019; Strydom et al., 2013). Given the finding that overall, the general population (World Health Organisation, 2022) and individuals with ID are living to an older age (McCarron et al., 2011; Braddock, 1999; Thornton, 2019), with the median age increasing from 25 to 49 to 60-61 from 1983 to 1997 to 2021 (Yang et al., 2002; White et al., 2023), it is important to consider how the intersectionality between age and disability impacts biological, psychological and social outcomes (Tsang et al., 2023).

Interventions for Dementia

Dementia has no known cure, and the focus of treatments have emphasised slowing down the biological progression of the disease, and promoting social and psychological wellbeing (Woods et al., 2014; Logsdon et al., 2007; Downs & Bowers, 2008; Kitwood, 1997). The need for a more holistic understanding of dementia is highlighted by Spector and Orrell (2010) in their biopsychosocial model of dementia. The model builds on Kitwood’s (1993) ‘dialectical model of dementia’, and accounts for the various influences on the development of dementia and the course of the disease, thus paving the way for developing interventions which tackle these factors (Spector & Orrell., 2010). For example, the model highlights the importance of an individual's existing cognitive reserve in line with Cognitive Reserve Theory (Stern, 2002), stating that the initial appearance of symptoms of dementia will be influenced by the amount of cognitive reserve available and the individualised ability for the brain networks to compensate for the damage caused by the dementia. Cognitive reserve theory may further explain why people with ID are at increased risk of dementia, in terms of a lower cognitive reserve (Takenoshita et al., 2023) and the impact of social inequalities in accessing suitable education provisions to support in building an early cognitive reserve (Emerson, 2021). This model highlights the need to identify psychosocial interventions for individuals with dementia, alongside biological treatments (Spector & Orrell, 2010). The medical model has provided core developments in dementia care, but it is important to additionally understand the need for psychosocial interventions alongside medication (Spector & Orrell., 2010). For example, medication demonstrates some side effects and an unclear evidence base for effectiveness (Prasher, 2004; Mohan, Bennett, & Carpenter, 2009; 2009b; Mohan, Carpenter and Bennett, 2009; Hanney et al., 2012; Eady et al., 2018).

Psychosocial Interventions

Consistent with this understanding, psychosocial interventions such as Cognitive Stimulation Therapy work to improve mental stimulation in line with the 'use it or lose it' hypothesis (Mincer & Ofek, 1982; (Lowe & Krahn, 1999). These theories state that the appropriate level of mental stimulation has the potential to slow down the cognitive deterioration experienced by individuals with dementia (Swaab et al., 2002; Salthouse 2006). Research has shown a relationship between mental stimulation and increased cognitive gains (Breuil et al., 1994; Spector et al., 2003).

Additionally, there is ample evidence for the effectiveness of Cognitive Stimulation Therapy for individuals with dementia across various domains including cognition and quality of life (Aguirre et al., 2013; Stewart et al., 2017; Woods et al., 2006).

Research on the psychosocial impact of living with dementia has emphasised that we should be working to improve the individual’s subjective experiences of their life (Tsang et al., 2023) and utilise a ‘whole person’ approach to caring for the needs of people with dementia (Rabins & Black, 2007). Various psychosocial interventions for dementia are recommended by the National Institute for Health and Clinical Excellence (NICE [NG97]). These interventions assess improvement using a variety of outcomes, from cognition to mood and self-confidence (Dugmore, Orrell, & Spector., 2015).

Psychosocial Outcome Measures for people with dementia

There is a lack of consensus on ‘gold standard’ outcome measures to evaluate the effectiveness of interventions for dementia in a variety of psychosocial domains such as well-being, mood and quality of life (Moniz-Cook et al., 2008). Despite a European consensus for the use of certain cognitive measures for dementia assessments, for example, the Alzheimer’s Disease Assessment Scale (ADAS-Cog), Cambridge Cognitive Examination-revised (CAMCOG-R) and Mini Mental State Examination (MMSE; Verhey et al., 2003; 2004), there is still little consensus on whether these measures are clinically meaningful within this population (Moniz-Cook et al., 2008).

When applied to other domains (excluding cognition), which assess the subjective experience of life and mental health for the individual, carers and network around the person with dementia, there is a further lack of clarity on both which outcome measures should be utilised to measure these domains and which domains are relevant (Moniz-Cook et al., 2008; Stoner & Spector, 2016). A review by Stoner et al. (2017) evaluated 12 existing positive psychology measures for individuals with dementia in order to support a more holistic understanding of dementia care. They emphasised the importance of improving the subjective experiences of the person with dementia (Stoner et al., 2017) by enhancing social and psychological factors (e.g., quality of life, attachment, comfort; Kitwood, 1997). Dementia research has often solely focused on aspects of 'decline' and people with dementia have been subject to pejorative narratives about their 'contribution to society' with little emphasis on improving their quality of life, often rooted in misperceptions about a loss of self, ageist beliefs and the biomedicalization of dementia (McColgan, 2004; Lyman, 1989).

Psychosocial Outcome Measures for people with ID

Similarly, people with ID have been subject to harmful narratives and have repeatedly been denied the right to high quality care driven by their experience of the care received (United Nations, 2006; Townsend-White et al., 2011). There has been a consistent (historical and ongoing) neglect of the rights of people with an ID and they have often suffered immense harm from the systems that should protect and improve their wellbeing (Bernal & Hollins, 1995; Sanders, 2009; LeDeR Report, 2022). Various government strategies such as 'Valuing People' and 'Valuing People Now' have been implemented to address the way in which people with ID are often stripped of their choice and control in how their care is implemented (Department of Health and Social Care 2001; 2010). One potential avenue to improve the quality of care for individuals with ID would be adequate quality monitoring of services, including outcome measure data from both proxy and the individual's reports of their own experiences of care (Townsend-White et al., 2011). Given that individuals with ID are at significantly increased risk of developing dementia compared to the general population (Strydom et al., 2009; Lott & Head, 2019; Strydom et al., 2013) it is crucial to consider how intervention and service quality outcomes are gathered within this population, to improve available services.

Psychosocial Outcome Measures for people with ID and dementia

There is a shortage of overall research for dementia in people with ID (Courtenay et al., 2010) and in turn, this extends to an even greater scarcity of literature on outcomes for this population. This population is often excluded from the health care decision making process (Haveman et al., 2009) likely due to the inaccessibility of current research methods, for example, the lack of adaptations to formal outcome measures for this population in order to ensure validity (Gjertsen, 2019; O'Keeffe et al., 2019). This inaccessibility of input in their care extends to a wider systemic barrier in accessing health and social care services for dementia compared to those who do not have ID, despite the elevated risk of developing a dementia in those with ID (World Health Organisation, 2000). For example, there is ample research that highlights the limited scope of dementia assessment tools for individuals with ID compared to those without ID (Zeilinger et al., 2022; Zeilinger et al, 2020).

Given that national policy and guidance aims to prioritise person centred dementia care for people with ID, including the development of adapted psychological interventions (Public Health England, 2018), there is a need to evaluate the effectiveness of such interventions. Outcome measures for people with ID tend to focus on the aspects of life which impact caregiving and practical care planning, such as cognition and Activities of Daily Living (ADLs). Chief Executive of the National Development Team for Inclusion highlighted a need to "start measuring life related outcomes rather than processes – look at how treatment enables the person to get on with the rest of their life” (National Development Team for Inclusion [NDTi], 2013), meaning that outcomes should also incorporate the individual’s subjective experience of life.

Rationale and aim

The current review aims to identify existing outcome measures for individuals with ID and dementia and evaluate the quality of these outcome measures. The study will focus the search on positive psychology and mental health outcome measures, rather than cognitive and ADLs measures of deterioration, in keeping with national guidance on prioritising person-centred care and general wellbeing for this population. In addition, there are existing reviews on cognitive assessment tools (Zeilinger et al., 2013; Elliot-King et al., 2016) and one aspect of positive psychology; Quality of Life (Tsang et al., 2023), but there have been no previous reviews of general positive psychology and mental health outcomes.

Positive psychology will be operationalised as any outcome measure which assesses improvements or decline in an individual’s subjective experience of life (e.g. psychological adjustment, social inclusion, satisfaction, happiness). Positive psychology is a growing field that opposes the perspective that mental health and well-being are solely reliant on the amelioration of illness and rather, proposes that the individual’s subjective experience of well-being and life satisfaction for the past, present and future are important tenets of good mental health (Seligman & Csikszentmihalyi, 2000; Slade, 2010). A framework developed by Keyes (2007), known as the Complete State Model of Mental Health identifies mental health as lying across two continua: mental illness symptoms and subjective well-being.

Within this review positive psychology will be defined broadly as any factor which assesses an individual’s subjective experiences of life (Slade, 2010), with the individual’s experience as a key determinant of ‘wellness’ (Public Health England, 2018). Mental health measures that identify diagnosable mental health conditions will be used alongside positive psychology measures, as often supports for people with ID and dementia will be determined by formal mental health diagnoses within a system that is heavily influenced by the presence or absence of certain diagnoses (e.g. legal requirements for capacity assessments, access to specific services).

The current review will use both of these concepts to identify existing mental health and positive psychology outcome measures for individuals with dementia and ID and will assess the quality of these measures, aiming to recommend measures which can be used for this population in future research.

Review Questions

- What measures of positive psychology and mental health have been used with individuals who have ID and dementia?
- What are the psychometric properties of these measures of positive psychology and mental health for individuals with ID and dementia?
- Which of the identified measures are suitable for use with individuals who have ID and dementia?

Method

Search Strategy

Three electronic searches on MEDLINE, PsychInfo and Web of Science were carried out in September 2023 including articles from 1946 to September 2023. The searches were limited to abstract and title across all search terms. The search used combined the following search terms: intellectual disability* OR downs syndrome OR learning disab* OR LD OR ID AND dementia OR Alzheimer* AND quality of life OR QoL OR quality OR well being OR wellbeing OR well-being OR life satisfaction OR adaptive functioning OR social adjustment OR successful ag* OR benefit* OR dignity OR social participation OR social inclusion OR happiness OR autonomy OR resilen* OR optimism OR mood* OR depressi* OR anxiety* OR anxious OR emotion* OR mental health OR stress* OR social support OR health* OR satisfaction OR wellness OR measure* OR valid* OR reliab* OR instrument* OR questionnaire* OR quiz OR test* OR scale* OR tool* OR intervention* OT assess* OR outcome* OR outcome measure* OR psychometric* OR evaluat* OR rating* OR screening*.

A total of 3826 references were screened by title, by abstract and then by full text with reference to the inclusion and exclusion criteria detailed below. The final review identified 10 studies as suitable for inclusion. Reference lists from relevant papers were also screened during the full text stage and this process identified two additional studies suitable for inclusion (see Figure 1 for a detailed summary of the screening process). A total of 12 studies were included in the review. It was initially unclear whether Dodd (2010) would be included, as the design was a conference abstract. Further details were gathered from the main researcher via email, and it was decided that this study would be included.

A second reviewer supported in screening a minimum of 10% of all full text articles, data extraction and methodological quality assessments. Ten percent was used as a minimum, but more than 10% of the articles were 2nd reviewed at each stage with any additional uncertainties. Any disagreements were discussed, and if a consensus could not be reached, a 3rd reviewer resolved these.

Inclusion criteria

- One or more positive psychology and/or mental health outcome measure.
- Outcome measure applied with at least one individual with a diagnosed ID and dementia.
- Include proxy outcome measures (e.g. with family/carer).
- All study designs were included.

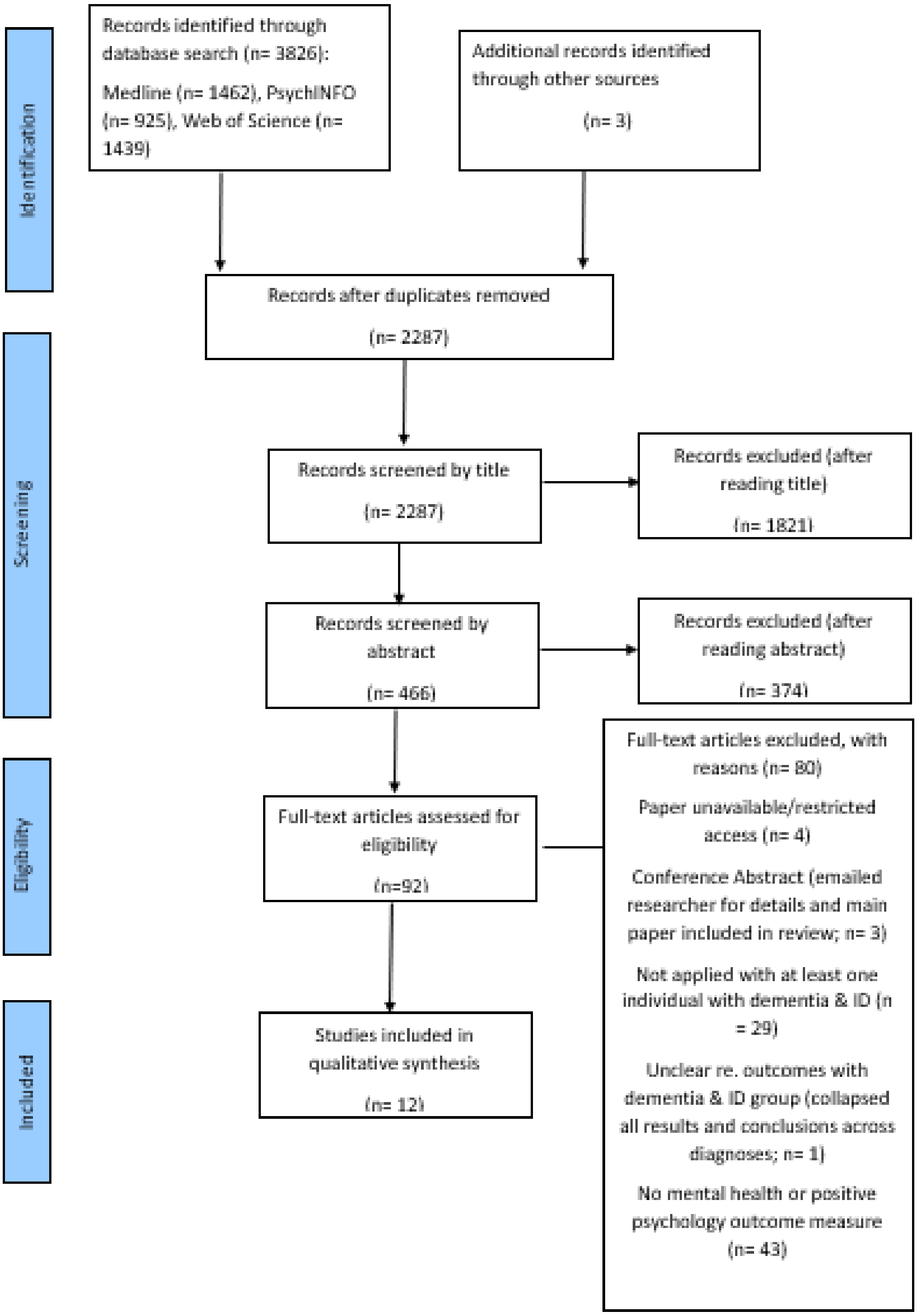
Exclusion criteria

- Only cognitive outcome measures included (assessing improvement/decline in cognitive domains).
- Only measures of ADLs included.
- Undiagnosed ID or dementia.
- Measure(s) solely used to assess for dementia or ID.
- Development of an outcome measure with no application with at least one individual with a diagnosed ID and dementia.
- Cannot be translated to English.

Conference abstracts with no further information from the main researcher.

Figure 1

Flowchart detailing the screening process and selection of suitable papers for review (Adapted from the PRISMA statement; Moher et al., 2009).



Quality Assessment Methodology

The methodological quality of each study in relation to each outcome measure was assessed using the COSMIN Risk of Bias Checklist (Mokkink et al., 2018; Prinsen et al., 2016; Terwee et al., 2018). As the inclusion of a wide variety of study designs is likely to impact the comparability of quality, these were not synthesised based on the COSMIN manual recommendations (Mokkink et al., 2018; Prinsen et al., 2016; Terwee et al., 2018). A narrative synthesis was utilised to discuss the suitability of included measures, rather than sole reliance on the descriptors of quality assigned to each outcome measure by the COSMIN checklist. The COSMIN risk of bias checklist is modular, which means that the quality assessment of the outcome measure was carried out based on the included measurement properties for each individual study. Due to the variation in study design, if a particular aspect of the risk of bias checklist was unreported, this section was reported as N/A. Each item on the checklist was rated using a scale from very good to adequate to doubtful to inadequate or not applicable (N/A). The COSMIN checklist uses the 'worst score counts' principle' for the final quality rating for each outcome measure (Tewee et al., 2012) and thus, the rating for each aspect of risk of bias will use this principle to appraise risk of bias.

In addition, the risk of bias assessment of each outcome measure does not include papers which have validated the measure outside of the target population (e.g. people with ID only or people with dementia only) as this is not in keeping with the initial aims of the systematic review, to identify existing measure of positive psychology and mental health outcome measures for people with ID and dementia.

Results

Descriptives

Twelve studies published between 1995 and 2023 were identified as suitable for inclusion. A total of 274 participants (*M* = 22.83, *SD* = 19.09) with ID and dementia across all studies were included in this review. Seven studies either did not report any information on gender, or the report of gender also included individuals who did not have a diagnosis of both ID and dementia. Across the remaining studies there was a higher proportion of females (*n* = 89) to males (*n* = 61). Similarly, six studies did not include the age range of participants or included individuals who did not have a diagnosis of ID and dementia within their report of age range. Of the remaining studies, the age range of included participants was 35 to 94. Only three studies (Ali et al., 2022; Ghazirad et al., 2022; DeVreese et al., 2012) included information about current mental or physical health comorbidities (*n* = 61) but the remaining studies did not include information about comorbidities or did not separate the reported comorbidities for the participants with or without ID and dementia.

The wider systematic review methodology was not based on the COSMIN procedure outlined by the COSMIN manual for systematic reviews of PROMS (Mokkink et al., 2018; Prinsen et al., 2016; Terwee et al., 2018) due to a limited number of available outcome measure validation studies. The review does not adhere to the exclusion criteria required by the COSMIN manual due to the scarcity of outcome measure validation studies within this population. For example, the current review uses an outcome measure reported within a conference abstract and measures used to evaluate the effectiveness of particular interventions, rather than the recommended validation studies.

Two out of the 12 studies were outcome measure validation studies (Dodd et al., 2015; DeVreese et al., 2012) and the remaining included studies were of varied designs. However, due to the sparsity of outcome measure for people with ID and dementia, the remaining 10 studies were included to capture all available positive psychology and mental health outcome measures for this population. Dodd (2010) was a conference abstract, however, despite the lack of a full write up, the key findings gathered from the main researcher were useful with regards to the utility of the DEMQOL and DEMQOL-Proxy within this population. Three studies trialled a particular intervention and these measure(s) were utilised to evaluate the outcome of these interventions. See Table 1 for a summary of all descriptive information and Appendix A for further specific detail (e.g. the number of total participants included in the study compared to the number of participants with a dementia and ID diagnosis).

Table 1

Summary of descriptive statistics for included studies

Study	N (dementia and ID diagnosis)	Comorbidities	Age Range	Gender M:F	Intervention
Ali et al., (2022)	40	Hearing problems (*n* = 9); visual problems (*n* = 6); Epilepsy (*n* = 8)	Not included	17:23	40 sessions of iCST
Cooper (1997)	29	Not included	69 – 94	10:19	N/A
DeVreese et al., (2012)	20	No current comorbidities	Includes ppts without diagnosed dementia and ID	Includes ppts without diagnosed dementia and ID	N/A
Dodd (2010)	13	Not included	43 – 68	Not included	N/A
Dodd et al., (2015)	Approx. 64	Not included	46 – 65	Not included	N/A
Finnamore & Lord (2007)	8	Not included	Not included	Not included	DCM
Forrester-Jones et al., (2017)	6	Includes ppts without diagnosed dementia and ID	Includes ppts without diagnosed	Includes ppts without diagnosed	N/A

			dementia and ID	dementia and ID	
Ghazirad et al., (2022)	1	Anaemia and Epilepsy	71	Not included	N/A
Moss & Patel (1995)	12	Not included	Not included	Includes ppts without diagnosed dementia and ID	N/A
Ryan & Dodd (2023)	49	Not included	Not included	21:28	N/A
Thompson (2003)	16	Not included	35 – 66	7:9	N/A
Watchman et al., (2021)	16	Not included	38 – 77	6:10	A selection of 2 to 6 interventions each

Note. ‘participant’ is abbreviated to ‘ppt’; ‘individualised CST’ is abbreviated to ‘iCST’; ‘Dementia Care Mapping’ is abbreviated to ‘DCM’

Across these studies, 11 different positive psychology or mental health outcome measures were identified, of which seven assessed positive psychology domains (Quality of Life; Goal Attainment) and four were measures of mental health (Mental Health Difficulties; Anxiety & Depression).

The positive psychology measures were: the Quality Outcome Measure for Individuals with Dementia (QOMID), The QoL Alzheimer’s Disease (QOL-AD), Quality of Life in Advanced Dementia (QUALID), Goal Attainment Scale, Dementia Care Mapping (DCM), Dementia Quality of Life (DEMQOL) and DEMQOL-Proxy. The mental health measures were: The Hospital Anxiety and Depression Scale (HADS), Neuropsychiatric Inventory Questionnaire (NPI-Q), The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) and Present Psychiatric State - Learning Disabilities (PPS-LD). Table 2 and 3 outline the key properties of each outcome measure.

It is useful to note that the all the included measures use varied modalities for collecting either positive psychology or mental health outcomes for participants. Most outcome measures were questionnaire based (QOMID; QOL-AD; HADS; QUALID; NPI-Q; DEMQOL and DEMQOL-Proxy). Two measures (PPS-LD and PAS-ADD) utilise an interview-questionnaire style, with a semi structured interview schedule (from participant or proxy) to inform the completion of a checklist by a qualified clinician. Two included measures utilise a process to evaluate a specific outcome (DCM; Goal Attainment Scale). DCM is a structured observation tool which uses a step-by-step process to evaluate current QOL, which informs a care plan to promote QOL. Thus, the DCM is both a tool for recording an outcome and the intervention itself. Similarly, the Goal Attainment Scale is an individualised step-by-step process tool, which is tailored to the person's specific goals and measures the extent to which these goals have been met.

Table 2

Summary of included outcome measures

Study	**Outcome Measure**	**Positive Psychology or Mental Health Measure**	**Proxy or Ppt**	**Country & Language**
Ali et al., (2022)	QOL-AD	PP: QoL	Proxy	UK, English
Ali et al., (2022)	HADS	MH: Anxiety and Depression	Proxy	UK, English
Cooper (1997)	PPS-LD	MH: Mental Health Difficulties	Proxy and ppt	UK, English
DeVreese et al., (2012)	QUALID	PP: QoL	Proxy	Italy, Italian
Dodd (2010)	DEMQOL	PP: QoL	Proxy and ppt	UK, English
Dodd (2010)	DEMQOL-Proxy	PP: QoL	Proxy	UK, English
Dodd et al., (2015)	QOMID	PP: QoL	Proxy only or Proxy and ppt	UK, English
Finnamore & Lord (2007)	DCM	PP: QoL	Proxy	UK, English

Forrester-Jones et al., (2017)	DEMQOL-Proxy	PP: QoL	Proxy	UK, English
Ghazirad et al., (2022)	NPI-Q	MH: Anxiety and Depression	Proxy	UK, English
Moss & Patel (1995)	PAS-ADD	MH: Mental Health Difficulties	Proxy and ppt	UK, English
Ryan & Dodd (2023)	QOMID	PP: QoL	Proxy and ppt (where possible)	UK, English
Thompson (2003)	HADS	MH: Anxiety and Depression	Not included	UK, English
Watchman et al., (2021)	QUALID	PP: QoL	Proxy	UK, English
Watchman et al., (2021)	NPI-Q	MH: Mental Health Difficulties	Proxy	UK, English
Watchman et al., (2021)	Goal Attainment Scale	PP: Goal Attainment	Ppt	UK, English

Note. italics are used to denote studies which have more than one outcome measure suitable for inclusion; 'positive psychology outcome measure' has been abbreviated to 'pp'; 'mental health outcome measure' has been abbreviated to 'MH'; 'participant' has been abbreviated to 'ppt'; 'quality of life' has been abbreviated to QoL.

Table 3

Included outcome measure properties

Outcome Measure	Validated in dementia and/or ID sample (example validation study or systematic review of psychometric properties)	Number of items and domains	Validation study included in review
QOMID	Dementia and ID ***(Dodd et al., 2015)***	17 items Person centred approaches to support; positive risk taking; respect for human rights; consistency of approach; interaction with others; emotional reassurance to cope with changes; orientation; daily living; carrying out preferred activities; flexibility of support; environment; behaviour; health; support from well-co-ordinated agencies; nutrition; mobility; continence	Yes
QOL-AD	Dementia (Thorgrimsen et al., 2003)	13 items	No

		Domains of physical health; energy; mood, living situation; memory; family, marriage; friends; chores; fun; money; self; life as a whole.	
HADS	Adapted version for ID (Dagnan et al., 2008) Dementia (Stott et al., 2017)	14 items 7 items for anxiety and 7 items for depression	No
QUALID	Dementia and ID in Italian sample ***(DeVreese et al., 2012)***	11 items Positive and negative QoL; mood; comfort; activities of daily life	Yes
NPI-Q	Dementia (Kaufer et al., 2000)	12 items Assessing delusions; hallucinations; agitation/aggression; depression/dysphoria; anxiety; elation/euphoria; apathy/indifference; disinhibition; irritability/lability; motor disturbance; nighttime behaviours; appetite/eating	No
Goal Attainment Scale	Dementia (Budgett et al., 2024)	Domains dependent on the individual's personalised goals	No
PAS-ADD	ID (Moss et al., 1998)	27 question items and 19 observational items	No
PPS-LD	None	116-item semi structured interview rating scale Assessing changed sleep pattern; loss of concentration; coarsening of personality; worry ; reduced quantity of speech; change in appetite; onset of or inc in verbal aggression; autonomic anxiety; social withdrawal/reduced social interaction; weight change; irritability; onset of or inc in physical aggression; onset of or inc reassurance-seeking/fearfulness; delusions; onset of or inc in agitation; loss of interests; loss of energy; visual hallucinations; misery; tearfulness; onset of or inc in tantrums; onset of or inc in other maladaptive behaviours; auditory hallucinations; diurnal mood variation; preoccupation with death	No
DCM	Dementia (Hughes et al., 2021)	2 mappers observe and allocate one of 24 behaviour category codes every 5 minutes Given a Wellbeing or Illbeing score (WIB) value, subjective state ranges from -5 to +5 Collects both quantitative and qualitative data	No
DEMQOL-Proxy	Dementia (Smith et al., 2007)	31 items Individual mood; memory concerns; worries/concerns about everyday lives over the past week	No
DEMQOL	Dementia (Smith et al., 2007)	28 items	No

	Individual mood; memory concerns; worries/concerns about everyday lives over the past week	

Note. ***Bold italics*** have been used to denote where the validation study has been included within the current review; ‘increased’ has been abbreviated to ‘inc’.

Methodological Quality Assessment

The full COSMIN appraisal process is detailed in Appendix B to ensure that the quality ratings remain transparent and replicable if required. In addition, although the ‘worst score counts principle’ is recommended by the COSMIN manual (Mokkink et al., 2018; Prinsen et al., 2016; Terwee et al., 2018), this principle fails to capture specific differences between each study. For example, where a study has a ‘very good’ rating for most reliability items, this method will prioritise the single ‘inadequate’ rating and will be rated the same as a study which has an ‘inadequate’ rating for all reliability items. The ratings based on the ‘worse score counts principle’ are displayed in Table 4 and will be reviewed alongside a narrative synthesis.

Many included studies did not report on many aspects of risk or bias, or this was not applicable to the study design. Three included studies were rated as not applicable for all items on the COSMIN checklist (Cooper, 1997; Dodd, 2010; Ghazirad et al., 2022). It is key to note that Dodd (2010) was not subject to the full quality appraisal as the study design (conference abstract) was not suitable for any section of the COSMIN appraisal.

Table 4

COSMIN risk of bias checklist

Study and Outcome Measure	PROM development	Content validity	Structural validity	Internal consistency	Cross-cultural validity/measurement invariance	Reliability	Measurement error	Criterion validity	Hypothesis testing for construct validity	Responsiveness
QOMID (Dodd et al., 2015)	Doubtful	Doubtful	Inadequate	V. Good	N/A	N/A	N/A	N/A	N/A	V. Good
QOL-AD (Ali et al., 2022)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	V. Good
HADS (Ali et al., 2022)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	V. Good
QOMID (Ryan & Dodd, 2023)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	V. Good
QUALID (Watchman et al., 2021)	N/A	N/A	N/A	N/A	N/A	Inadequate	N/A	N/A	N/A	Doubtful
Goal Attainment Scale (Watchman et al., 2021)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	V. Good
NPI-Q (Watchman et al., 2021)	N/A	N/A	N/A	N/A	N/A	Inadequate	N/A	N/A	N/A	Doubtful
PAS-ADD (Moss & Patel,1995)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	V. Good	V. Good	N/A
PPS-LD (Cooper, 1997)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DCM (Finnamore & Lord, 2007)	N/A	Doubtful	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
HADS (Thompson, 2003)	N/A	N/A	N/A	N/A	N/A	Inadequate	N/A	N/A	N/A	V. Good
DEMQOL-Proxy (Forrester-Jones et al., 2017)	N/A	N/A	N/A	V. Good	N/A	N/A	N/A	N/A	N/A	N/A
QUALID (DeVreese et al., 2012)	N/A	N/A	Inadequate	V. Good	N/A	Adequate	N/A	N/A	V. Good	Adequate
DEMQOL (Dodd, 2010)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
DEMQOL-Proxy (Dodd, 2010)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
NPI-Q (Ghazirad et al., (2022)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Note. ‘very good’ abbreviated to ‘v. good’; scale runs from very good - adequate - doubtful - inadequate - N/A.

PROM development

Dodd et al. (2015) was the only study which included a measure which was developed for people with ID and dementia. Despite the ‘doubtful’ risk of bias rating, the QOMID is the only positive psychology outcome measure designed with this population in mind.

Content validity

Content validity was assessed by two studies, and both were appraised as ‘doubtful’ (Dodd et al., 2015; Finnamore & Lord, 2007). Dodd et al. (2015) used a face validity trial to assess whether proxies (e.g. carers) were able to understand and use the QOMID. In addition, the main aim of the study was to assess clinical utility of the QOMID, and outcomes were gathered in relation to comprehensiveness, comprehensibility, and relevance of the measure for professionals. Qualitative feedback from the face validity trial was noted to be ‘good’ and some adaptations were made to the final measure based on this trial. Finnamore and Lord (2007) did not assess content validity as extensively but did include staff subjective report on how they found the process of coding participant wellbeing/illbeing score (WIB). They found that generally, staff did feel that this score was reflective of the participants’ experiences. Despite have a similar risk of bias rating for content validity, the QOMID demonstrates a more thorough assessment of content validity.

Structural validity

In terms of structural validity, both the QOMID (Dodd et al., 2015) and the QUALID (DeVreese et al., 2012) included a suitable factor analysis, however, both were rated as ‘inadequate’ quality overall. Dodd et al. (2015) was slightly better in quality, as they used an exploratory factor analysis, whereas DeVreese et al. (2012)

used a principal component analysis (PCA) which is deemed to be less robust. However, no study utilised a ‘gold standard’ confirmatory factor analysis.

Internal consistency

The QOMID (Dodd et al., 2015), DEMQOL-Proxy (Forrester-Jones et al., 2017) and QUALID (DeVreese et al., 2012) assessed internal consistency. All studies were rated as ‘very good’ where Cronbach’s alpha was above the 0.70 required threshold (BPS, 1992) for good internal consistency (α = 0.848; 0.79; 0.80 respectively).

Cross-cultural validity/measurement invariance

Measurement invariance was not assessed using the appropriate statistical methods for any study (e.g. multi-group confirmatory factor analysis and thus was not rated in any study.

Reliability

Three studies included information on reliability analyses, or included some analyses which could be interpreted with reference to reliability. However, DeVreese et al. (2012) was the only included study which used specific intraclass correlation coefficient (ICC) analyses with reference to inter-rater and test-retest reliability. Both analyses demonstrated high correlation coefficients, and the scores were not significantly different, indicating good inter-rater and test-retest reliability. However, there was little explicit information on whether the respondents were stable in terms of quality of life across the two time points and no indication as to whether the test conditions were similar. The other two studies, Watchman et al. (2021) and Thompson (2003) alluded to reliability stating that there was a correlation between the scores of the QUALID (Watchman et al., 2021), NPI-Q (Watchman et al., 2021) and that the scores were stable on the HADS (Thompson, 2003) at various time points, but these analyses were not followed up with significance testing.

Measurement error

None of the included studies made reference to or analysed measurement error (random and systematic error).

Criterion validity

Moss and Patel (1995) assessed one aspect of criterion validity, where they determined that the PAS-ADD was sensitive enough to detect changes in mental health symptoms for those with dementia and ID compared to those without or with suspected dementia. This sensitivity did not extend to those with dementia and those without dementia (excluding suspected dementia cases). However, it is useful to note that good sensitivity and specificity describes the ability of a measure to correctly identify those with (sensitivity) and those without the condition (specificity). This is only true for the PAS-ADD in those with dementia and ID. Although criterion validity is rated ‘very good’ for the target population, the sensitivity and specificity of this measure is specific to the target population rather than the measure itself. Other included studies made some reference to sensitivity, but this was not in the context of criterion validity, thus were rated as N/A.

Hypothesis testing for construct validity

Hypothesis testing for construct validity was not explicitly reported by most included studies. They did not directly refer to statistical methods which assessed convergent validity (comparing the outcome measure with other similar outcome measures) and discriminative or known-groups validity (comparing the results for different subgroups that are expected to differ on the construct). Two studies did report on construct validity, including DeVreese et al. (2012) for the QUALID and Moss and Patel (1995) for the PAS-ADD. DeVreese et al. (2012) reported construct convergent validity with the AADS, whereas Moss and Patel (1995) reported a discriminant function analysis (known groups validity) for the PAS-ADD (comparing the subgroups of people with dementia vs no dementia on various constructs of the PAS-ADD), with all factors rated as ‘very good’ for both.

Therefore, the other studies which did compare outcome measures to other similar measures or compared across various subgroups (but did not use specific methods for convergent or discriminant validity) were included in the quality ratings for responsiveness rather than construct validity.

Responsiveness

The final COSMIN item was responsiveness and was split into four different measures of responsiveness: 1) comparison to a gold standard, 2) comparison with other outcome measure instruments, 3) hypothesis testing: comparison between subgroups and 4) hypothesis testing: before and after intervention).

None of the included measures included a gold standard comparison. Given that there is no recommended gold standard measure of quality of life or mental health for this population, this measure of responsiveness is understandably, ‘not applicable’ across all included studies.

Comparisons with other outcome measure instruments were included for two measures in one study: NPI-Q and the QUALID (Watchman et al., 2021). Watchman et al. (2021) clearly stated which instrument was used for comparison, where they compared the scores for the QUALID and NPI-Q with each other. Watchman et al.

(2021) reported few measurement properties for the comparator instrument, so both comparisons were scored as ‘doubtful’.

Four studies used hypothesis testing to compare between subgroups (Ryan & Dodd, 2023; Dodd et al., 2015; Thompson, 2003; DeVreese et al., 2012). All studies scored ‘very good’ across all factors (adequate description of important characteristics across all subgroups, appropriate statistical methods and no other important flaws in the design or method). However, each study did vary in the subgroups used for comparison. Ryan and Dodd (2023) compared those with early and mid-stage dementia (all had DS) on each domain of the QOMID. Similarly on the same measure, Dodd et al. (2015) compared across dementia status, but additionally included living arrangements and ID (compared to those who did not have an ID) but on other factors relating to how easy it was to use the QOMID. DeVreese et al compared those with or without a dementia diagnosis on the QUALID (all had an ID diagnosis) and Thompson (2003) compared the non-DS and DS groups on the HADS.

Three included studies applied an intervention (Ali et al., 2022; Watchman et al., 2021; Finnamore & Lord, 2007) but only Ali et al. (2022) and Watchman et al. (2021) used formal statistical methods to test hypotheses before and after an intervention. Both studies were rated as ‘very good’ for all quality criteria.

Quality assessment summary

For positive psychology outcome measures, use of the QOMID by Dodd et al. (2015) and the QUALID by DeVreese et al. (2012) generated the most comprehensive risk of bias assessment. Information for five risk-of-bias criteria was available, despite overall ‘inadequate’ ratings. For the two other studies which used the QOMID (Ryan and Dodd, 2023) and QUALID (Watchman et al., 2021), we could infer that they would have a similar quality assessment to Dodd et al. (2015) and DeVreese et al. (2012) had they included further risk of bias factors.

For mental health outcome measures, there was an overall lack of risk of bias outcomes, where the highest number of assessed criteria was two. The PAS-ADD by Moss and Patel (1995) assessed two risk of bias criteria, scoring the highest overall. This was followed by the HADS (Thompson, 2003) and NPI-Q (Watchman et al., 2021) both scoring ‘inadequate’ overall. However, with a maximum of two risk of bias criteria, it could be argued that there is limited assessment of risk of bias in order to draw any effective conclusion about the overall risk of bias across these studies.

In terms of other measures in studies which assessed one or no criteria, we could argue that the overall risk of bias rating for these studies are meaningless if most other criteria were not assessed within the study. The risk of bias and usefulness of these measures for individuals with dementia and ID is unknown, due to the high volume of ‘not applicable’ across the risk of bias ratings.

Narrative Synthesis

Table 5 includes further qualitative and quantitative information on feasibility and sensitivity of these measures for people with ID and dementia. Feasibility was defined as any reported details on the ease of use of the measure (e.g. administration, understanding the wording) for this population (with the individual and/or proxies). Sensitivity was defined as the ability of each outcome measure to distinguish between the different classifications of the domain that is being measured for this population. For example, whether a quality-of-life measure demonstrated varied scores for people with ID and dementia based on their varied quality-of-life outcomes, without an overall ceiling or floor effect in scores.

As the methodological quality assessment captured validity, reliability and some sensitivity information, the narrative synthesis will focus on the feasibility and qualitative report of sensitivity alongside the overall methodological quality assessment to determine which measures are the most suitable, least suitable or lack information on their suitability, for those with dementia and ID.

Table 5 also highlights some other key methodological variation across studies and these details were often not captured by the methodological quality assessment. Thus, although the general outcome or conclusion may have found that the measure was suitable for use in this population, this conclusion may have been based on varied proportions of people with ID and dementia or subject to other methodological considerations. For example, Dodd et al. (2015) combined the analysis for those with suspected and early-stage dementia and some individuals without a diagnosed ID (11%) were included in the overall analyses. This suggests that the conclusions drawn about the utility of this measure for this population may have been drawn from individuals who would not be considered within this population.

Positive Psychology Outcome Measures

Considering that the QOMID by Dodd et al. (2015) and the QUALID by DeVreese et al. (2012) had the most detailed quality assessment across all measures, both were also reported to be feasible to use with people who have ID and dementia. Overall, the QOMID in Dodd et al. (2015) was described as generally easy to use and a good measure for people with dementia and ID. The other QOMID study by Ryan and Dodd (2023) did not include any information on the feasibility of the measure with their sample of people with ID and dementia. For both QUALID measures, DeVreese et al. (2012) reported a less detailed assessment of feasibility, finding no issues with administration and good response rates, but the other QUALID study by Watchman et al. (2021) did not report on the feasibility of the measure with their participants.

The DEMQOL-Proxy appeared to not to be feasible for use with the population based on the further details gathered from Dodd (2010), as staff members struggled to respond on behalf of participants. Forrester Jones et al. (2017) did not include any information on the use of the DEMQOL-Proxy for people with dementia and ID. Similarly, Dodd (2010) found that the DEMQOL was an unsuitable self-report measure for people with dementia and ID with too many complex concepts. It could be tentatively (due to limited methodological quality assessment) concluded that the DEMQOL and DEMQOL-Proxy may be unsuitable for use with people who have dementia and ID.

The only other measure reported as suitable for use for this population was DCM (Finnamore & Lord, 2007) where all outcomes were completed as required and no issues noted. For the Goal Attainment Scale (Watchman et al., 2021) and QOL-AD (Ali et al., 2022) there was no information about the feasibility of using this measure for people with ID and dementia. In terms of methodological quality, all three measures included only one aspect of risk of bias. The DCM may be useful if validated for use with people who have dementia and ID.

Mental Health Outcome Measures

Moss and Patel (1995) found that the individuals with dementia and ID struggled to complete the PAS-ADD compared to those without dementia, therefore having to rely fully on proxy report (for which no other issues were reported). Cooper (1997) found that the PPS-LD completion rates were good overall. However, some specific symptoms of psychosis and depression which can only be identified with self-report, were difficult for individuals with little verbal communication ability to report on. The two remaining mental health outcome measures were the HADS (Ali et al., 2022; Thompson, 2003) and NPI-Q (Ghazirad et al., 2022; Watchman et al., 2021), both of which did not include any further details on the feasibility of completing this measure with people who have ID and dementia.

Table 5

Further qualitative and quantitative information for included studies

Study	Outcome Measure(s)	Other methodological considerations	Feasibility	Sensitivity
Ali et al., (2022)	QOL-AD HADS	Excluded people with severe dementia and significant physical illness/disability, visual or hearing impairments or behavioural problems preventing participation in iCST.	Not included	Not included
Cooper (1997)	PPS-LD	Did not report the outcome or any results from the measure in the paper.	Completion rate: 93.7% Difficulty assessing some symptoms of psychosis and depression which rely on communication abilities to describe subjective experiences.	Not included
DeVreese et al., (2012)	QUALID	Did not separate the analysis for those with dementia compared to those without dementia.	No issues with administration. Proxy response rate: 100%	Measure was sensitive to some changes in QoL between those who have dementia and no dementia.
Dodd (2010)	DEMQOL DEMQOL-Proxy	Conference presentation, not a full research paper. Included 8 ppts with suspected dementia in main analysis and 10 ppts with no diagnosed dementia.	**DEMQOL** Completion rates: No attempt (*n* = 5) Abandoned (*n* = 21) Struggled (*n* = 1) Ok to use (*n* = 2) – both had no dementia Easy (*n* = 2) – 1 had no dementia and 1 had suspected dementia Most ppts with dementia struggled, abandoned or did not attempt. Understood wording: Understood a lot (*n* = 0) Understood some (*n* = 4) Didn’t understand (*n* = 21) Not specified (*n* = 6)	Not included

			Too difficult for people with ID: complex concepts required (e.g. understanding memory, worry about and backwards time). **DEMQOL-Proxy** Ease of use: Easy (*n* = 8) OK (*n* = 12) Struggle (*n* = 9) Residential staff reported finding it difficult to respond on behalf of the ppts. Both measures unsuitable for this population.	
Dodd et al., (2015)	QOMID	Analysis included those with suspected (no diagnosed dementia) and early-stage dementia and some ppts with no diagnosed ID (11%). Unclear information on who completed the measure (proxy reports informed by the individual OR solely by professionals and used to inform the individual's care).	Clinical Utility: 95.5% found clarity of instructions easy/fairly easy, 4.5% found it difficult/very difficult 92.5% found ease of use easy/fairly easy and 7.5% found it difficult/very difficult 79.1% found ease of assigning dementia stage easy/fairly easy, 20.9% found it difficult/very difficult 15 to 120 mins to complete (mean of 31-45 mins) - n=66 Minimal differences between utility of QOMID based on dementia stage but overall use of the tool rated as 'Good'	Sensitivity of measures: no significant differences on scores based on living arrangements or dementia status. No significant difference between older adults with ID and no ID (all diagnosed with dementia).
Finnamore & Lord (2007)	DCM	Some qualitative and some quantitative data gathered by the outcome measure. DCM is both the intervention and the measure of wellbeing	All mappers completed the required number of observations and maps.	Not included
Forrester-Jones et al., (2017)	DEMQOL-Proxy	Analysis included those with and without a diagnosis of dementia.	Not included	Not included
Ghazirad et al., (2022)	NPI-Q	Single case study design with no group comparisons. Only included a qualitative description of comparisons with other outcome measures (no statistical analyses).	Not included	Qualitatively sensitive to longitudinal changes in neuropsychiatric symptoms
Moss & Patel (1995)	PAS-ADD	Outcome measure factor structure is unclear across the literature and there were no details on the	Only 4/12 with confirmed dementia were able to complete the full interview on the PAS-ADD (21%). 56% of	PAS-ADD is sensitive enough to detect changes in mental health symptoms in those with dementia and ID (compared to

		factor analysis included in the paper. Only sensitivity was calculated (not specificity).	those without dementia were able to complete the interview. Analysis could not use participant interviews: relied solely on proxy interviews.	those without or with suspected dementia) but not between those with dementia and those without (excluding suspected cases) A discriminant function analysis found higher scores for those with dementia on: loss of interest, sleep difficulty, irritability, slowness, poverty of speech & lower scores for those with dementia on: depressed mood and delayed sleep.
Ryan & Dodd (2023)	QOMID	No information on how many dementia diagnoses were highly suspected rather than confirmed.	Not included	No differences in achievability of domains between different stages of dementia. Some domains were more achievable for people with ID and dementia than those without dementia: emotional reassurance to cope with changes, nutrition and mobility were more achievable than environment and person-centred approaches to support
Thompson (2003)	HADS	Limited details provided.	Not included	Sensitivity (sensitive enough to detect changes in DS and non-DS group to a similar extent): No significant difference between non-DS and DS group on the HADS at either time point
Watchman et al., (2021)	QUALID NPI-Q Goal Attainment Scale	The QUALID was only used in one part of the study (cycle 2 of 2). **QUALID & NPI-Q** Did not explicitly refer to test-retest reliability but it was inferred based on the correlation type and result.	Not included	Not included

Discussion

This systematic review aimed to identify and understand the psychometric properties of positive psychology and mental health outcome measures for people with ID and dementia. This is particularly important when developing psychosocial interventions to improve outcomes for this population. Such interventions will require a reliable and valid method of quantifying subjective experiences and improvements in general wellbeing. Despite the non-stringent inclusion criteria, this review identified seven positive psychology and four mental health outcome measures. As a population whose personal experiences of life are rarely considered both within research and clinically, it is unsurprising that the psychometric properties of all included measures were scarce or of a poor overall quality. The QOMID is an important measure of quality of life that was developed with this population in mind, despite demonstrating poor overall methodological quality. This was followed by the Italian version of the QUALID, also a measure of quality of life but not developed specifically for this population. There were no mental health measures that exceeded in methodological rigour or feasibility for use with this population.

Strengths and limitations

Due to the non-stringent inclusion criteria, most measures were not validation studies, which would likely have yielded a smaller number of potential outcome measures. It could be argued that having a larger number of measures of unknown quality is less helpful for understanding which measures are suitable for use within this population. However, based on the current finding, this would have likely identified one result (the QOMID), and no other information on the lack of suitability of other measures. For example, Dodd (2010) would have been excluded as a conference abstract. However, the results from Dodd (2010) highlighted some key findings about the unsuitability of the DEMQOL and DEMQOL-Proxy for this population, providing useful information for clinicians and researchers in choosing a suitable outcome measure. In addition, this review generated a variety of measures that did show some feasibility with this population, providing a promising avenue for future research in validating these measures for people with dementia and ID.

The COSMIN manual highlights that including a range of study designs rather than solely outcome measure validation studies are likely to interrupt the standardisation of the quality appraisal process. As such, it is important to interpret the quality appraisal results with caution. Given that the included studies were of varied designs, it could be argued that applying a methodological quality assessment (for outcome measure validation studies) provided limited information on the psychometric properties of these measures and on the feasibility of completing these measures with this population. However, all studies which use any outcome measures, regardless of design, should include information on some psychometric properties to provide a rationale as to why a particular measure was selected for use. As this information was not available for many of the included studies for use with this population, the validity and reliability of using these measures remain unknown. Therefore, any conclusions from such research does not hold the same weight as a study which does use a measure that is validated for use within the population of interest.

Around four studies drew conclusions from summary statistics that captured individuals without dementia and ID or those with suspected dementia rather than a diagnosis of dementia. Additionally, the variation in terminology regarding a diagnosis of dementia led to some difficulties in synthesising these findings. One specific example is the group ‘early dementia’ compared to the group ‘suspected dementia’. Across all papers it was unclear as to whether those with early or suspected dementia were on similar treatment pathways or whether further investigation was required in order to confirm a diagnosis of dementia. It could also be speculated that individuals at the early or suspected stage may be functioning at a higher level, and therefore may not present in a similar way to those with confirmed or mid to late-stage dementia. In line with findings from Dodd (2010), where those with diagnosed dementia struggled to engage with the DEMQOL at all, one individual with suspected dementia and two with no dementia were able to complete the measure. Similarly, Moss and Patel (1995) found that only 21% of individuals with a diagnosed dementia and ID were able to complete the measure, compared to 56% of individuals with an ID but no diagnosed dementia. Therefore, when the analysis is collapsed across different groups of varied abilities, it is difficult to draw an overall conclusion as to the utility of these measure for all individuals with dementia and ID, as their ability to engage with the measures will likely be dependent on the stage and severity of dementia (and ID).

Another limitation was the lack of variety, especially for positive psychology measures. Positive psychology in the current review aimed to span across a variety of domains that referred to an individual’s subjective experience of life. Most included measures related to quality of life and one measured goal attainment. However, it is useful to note that quality of life was operationalised in a varied manner across the different measures (see Table 3). Therefore, despite the homogeneity in the type of positive psychology measure, it is important to look at the domains captured by each measure to conclude which aspects of quality of life are captured by each measure.

Many of the included studies did have a small overall number of participants (1 to 64) and would not be considered a psychometric validation study at this level (regardless of the research design used; White 2022). Therefore, although some conclusions can be drawn in terms of which measures could be useful or less useful, it is important to note that the results may not be generalisable. This is demonstrated by some included studies which have used the same outcome measures with varied results. For example, the NPI-Q in Watchman et al. (2021) and in Ghazirad et al. (2022) had completely different quality assessments. These findings indicate that although the group is not homogenous, there may be a further aspect relating to power and sample size, meaning that any key findings may not be reliable and other effects may go undetected due to a lack of statistical power.

Implications for future research

It is important to acknowledge the heterogeneity of any ID sample, even within the same ‘diagnostic’ category. For example, individuals with a mild ID will present with their own specific set of strengths and weaknesses. Further research may benefit from using widely recognised definitions for the different stages of dementia or specifying the exact differences between each category (e.g. between suspected and early stage) to avoid conclusions being drawn from heterogenous groups of individuals. Additionally, running analyses with each sub-group may be helpful in order to draw valid conclusions about the feasibility of a particular measure for people with dementia and ID at each stage of dementia (suspected, early, mid or late) and/or ID diagnosis (e.g. mild, moderate, severe or profound).

Given that all included studies demonstrated smaller sample sizes, it is important to consider the challenges of recruiting a suitable sample size, which is a key difficulty within ID research (Hilgenkamp et al., 2011). With the additional criteria of diagnosed dementia, there is a further limitation that must be met in an already difficult to recruit population. Therefore, future research could aim to understand some of the barriers to recruitment and retention in order to promote better overall quality research for people with ID and dementia.

Based on the limited variety of positive psychology measures included within the current review, future research should aim to include additional measures of subjective well-being with the aim of improving other positive psychology domains for people with ID and dementia. Individuals with ID are less likely to be encouraged to develop various positive psychology domains in their day-to-day life, where research may emphasise ADLs and behaviour, over their subjective well-being (NDTi, 2013). Therefore, future research on positive psychology outcome measures for people with ID and dementia will likely pave the way for encouraging interventions which focus on these domains for this population.

Implications for practice

The current review demonstrated that the two feasible measures with the most detailed quality assessments included one measure specifically developed for people with dementia and ID (QOMID) and another measure designed for people with late-stage dementia (QUALID). Measures which were not so feasible for use with this population were those in which the terminology and items within the measure related to complex concepts such as backwards time and worry about a particular aspect of functioning (e.g. the DEMQOL in Dodd, 2010). A suggestion may be adapting existing measures to remove abstract items or using measures such as the QUALID which have been used in other groups of individuals who may have similar needs (e.g. individuals with late-stage dementia rather than early-stage or suspected dementia).

With other included outcome measures, some were unsuitable for use (e.g. DEMQOL and DEMQOL-Proxy; Dodd, 2010). Other identified measures may benefit from further adaptation for use with those who have ID and dementia. For example, Cooper (1997) found that the PPS-LD was generally suitable for use, except for some self-report symptoms, specifically for depression and psychosis domains. These items relied on the individual's verbal self-report of their own experiences, which proved to be difficult for some people with dementia and ID. However, this could be remedied with the use of further adaptations such as alternative and augmentative communication (AAC). For example, a talking mat methodology is one method that is often used to support individuals with limited verbal communication in conveying their thoughts and feelings (Stans et al., 2019).

Conclusion

There is an overall lack of available research for people with ID and dementia. The current review demonstrated that this inequality extends to a lack of validated positive psychology and mental health outcome measure studies for people with ID and dementia. This study found one quality of life outcome measure (the QOMID) which was developed for use within this population, but the research for this measure is still in its infancy (e.g. small sample size). The QUALID was also identified as a potentially suitable measure of quality of life for people with ID and dementia. All other measures either demonstrated a lack of thorough psychometric assessment (e.g. validity and reliability analyses) and/or were not feasible for use within this population.

In light of national initiatives and a growing understanding that people with ID deserve to access the same support available to the non-ID population, further high-quality research is required for people with dementia and ID. This includes the evaluation of existing positive psychology and mental health outcome measures for people with ID and dementia, alongside the development of further outcome measures, if required.

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PART 2: EMPIRICAL PAPER

Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A qualitative exploration of feasibility and acceptability

Abstract

Introduction: Despite an elevated risk of developing dementia for people with intellectual disabilities (ID), there are no recommended psychosocial interventions. Group Cognitive Stimulation Therapy (CST) is the main NICE recommended psychosocial intervention for dementia. Individual CST has been trialled for people with ID and dementia, but group CST has not yet been trialled. The current qualitative study aimed to investigate the acceptability and feasibility of an adapted version of group CST for people with ID and dementia (CST-IDD). **Methods:** Twenty semi-structured interviews were carried out (8 facilitators; 6 carers; 5 people with ID and dementia [ID&D]) following five CST groups within a larger feasibility randomised controlled trial across six NHS sites. Interview data from people with ID&D was supplemented with a Talking Mat. An inductive and deductive approach to thematic analysis was used for data from facilitators and carers, and content analysis for data from people with ID&D. **Findings:** Acceptability of CST-IDD varied, depending on attendance and perceived outcomes of the group. There were limitations to consistent attendance for some group participants compared to others where attendance was not an issue. Acceptability increased with fewer barriers and many enablers in place. However, with an increasing need for certain requirements to promote acceptability of CST-IDD, feasibility reduces, as acceptability of the group is dependent on these conditions. One particular group and certain group attendees demonstrated positive perceived outcomes and good attendance despite some barriers. **Discussion:** Several enablers and barriers were important in determining the acceptability and feasibility of CST-IDD. Using the available data, the heterogeneity within this population demonstrated that acceptability and feasibility were heavily influenced by

individual needs and differences. Limitations and recommendations for future research are discussed.

Introduction

Dementia and Intellectual Disabilities (ID)

Within the general population, with an increase in life expectancy, there has been an associated rise in the prevalence of age-related conditions such as dementia (World Health Organisation, 2001). It has become imperative to expand research and evidence-based interventions for dementia (Prince, 1997; Wancata et al., 2003). For the ID population, there is an even greater proportion of individuals, compared to the general ageing population, who develop dementia (Strydom et al., 2013; Cooper, 1997). In particular, individuals with Down's syndrome (DS) have a cumulatively elevated risk of dementia with age (Rabe et al., 1990; Visser et al., 1997), where 77% of individuals aged 60 to 69 with DS have a dementia (Ballard et al., 2016). Those with ID are also more likely to develop dementia at a younger age than the general population (Evans et al., 2013; MacDonald & Summers, 2020).

There are similarities in the clinical presentation of dementia between individuals with and without ID, including difficulties with memory, mood, personality, executive changes and sensory sensitivities (Janicki & Dalton, 2000). However, there are variations between the timeline of these changes, for example, with ID, dementia is likely to initially present with personality and behavioural changes, compared to the general population, where lapses in memory are often an initial symptom (MacDonald & Summers, 2020). The consequences of dementia for those with ID are marked in comparison to those without ID, where the development of dementia is associated with faster progression of the disease and elevated mortality rates (Coppus et al., 2006; Strydom et al., 2013).

There are additional complexities in diagnosing dementia for people with ID, where the heterogeneity of cognitive ability within this population, makes it difficult to find a suitable benchmark for comparison (Stanton & Coetzee, 2004). Therefore, longitudinal assessments are recommended, leading to potential delayed diagnoses (Krinsky-Mc Hale & Silverman, 2013). In addition, diagnosing dementia for individuals with severe to profound ID can be limited by the lack of suitable baseline assessment tools. With no suitable baseline comparison due to ‘floor’ performance across all tests, it is difficult to establish any significant decline in functioning (Evans et al., 2013; McKenzie et al., 2018). Additionally, as individuals with dementia and ID may have limited verbal communication abilities, their subjective report of any changes are rarely considered (Smiley & Cooper, 2003).

Interventions for dementia in people with ID

Drug-based interventions demonstrate limited effectiveness and are often not suitable for all individuals with dementia, especially for those with ID (Courtenay & Eadie, 2014). The National Institute of Health and Care Excellence (NICE) guidelines for dementia [NG97] recommend person centred care and psychosocial interventions. Given that individuals with intellectual disabilities are living longer, there is also a need for person centred advance care planning in order to promote positive outcomes (McGinley & Knoke, 2018). However, despite an increased risk for dementia in those with ID, there has been limited research on psychosocial interventions (Watchman, 2014). People with ID are often excluded from person-centred care initiatives (Hahn, Fox & Janicki, 2015; Tuffrey-Wijne et al., 2016), and this extends to the management of dementia (Watchman, 2014).

Cognitive Stimulation Therapy (CST) for dementia

CST is the NICE recommended psychosocial intervention for mild to moderate dementia [NG97]. It is a 14-session group intervention which incorporates various person-centred principles such as: implicit rather than explicit teaching, continuity and consistency to improve recall and creating new associations in the brain by encouraging the generation of new ideas rather than rote recall (Spector, Gardner, & Orrell, 2011). CST has demonstrated improvements in various outcomes, including: cognition, language, working memory, depression, communication and quality of life (Desai et al., 2024). The benefits of CST are independent of the use of acetylcholinesterase inhibitor (AChEI) medication alongside the intervention (Aguirre et al., 2013) and is just as cost-effective (Knapp et al., 2006).

CST adaptations.

CST has been successfully adapted, for example, to include additional sessions (Maintenance CST; Orrell et al., 2014) and individualised (Individual CST; Orgeta et al., 2015; Yates et al., 2015). The intervention has been globally trialled (e.g., Raghuraman et al., 2017; Mkenda et al., 2018; Carbone et al., 2021; Yamanaka et al., 2013) and in many languages (CST by Country & CST Manuals, University College London, n.d.). In terms of other clinical populations, CST has been adapted for dementia (or mild cognitive impairment) in Parkinson’s disease, demonstrating benefits for family carers and participants (Leroi et al., 2019). However, the use of CST for dementia alongside other conditions is still in its infancy.

CST for dementia in people with ID

Given that individuals with ID are more likely to develop dementia and the limitations of drug-based interventions for dementia in people with ID (Courtenay & Eadie, 2014) such as fewer long-term benefits and increased side effects, there is a need for evidence based psychosocial interventions.

A review on psychosocial interventions for individuals with an ID and dementia (MacDonald & Summers, 2020) categorised interventions by type: behavioural, systemic and therapeutic. They noted a limited number of direct therapeutic interventions with the individual, but rather, many interventions were carried out with the system around the person. Most of the therapy interventions did not withstand the methodological quality assessment, with many deemed to lack methodological rigour. The studies also lacked representation of the voice of the person with dementia and ID (e.g. often focusing on the views of carers or observation tools). The lack of such representation demonstrates the pervasive impact of excluding people with ID from research (Chapman & McNulty, 2004; DiLorito et al., 2018). This emphasises the need to include the views of people with ID to represent their voice within intervention literature (Muralidhar et al., 2024). Various methods of alternative and augmentative communication (AAC) have been used to support and enable the voice of people with dementia and ID (Brewster, 2004; Murphy et al., 2007). The Talking Mat methodology, developed by Murphy and Cameron (2007), uses symbols and images to support individuals with communication impairments to express their views. Talking Mats are a helpful method of AAC for those with ID (Brewster, 2004) and dementia (Murphy et al., 2007). One case study for an individual with dementia and ID demonstrated that this methodology was successful but requires a basic level of communication (Bell et al., 2009).

In terms of group CST, there is one non-published dissertation which piloted group CST for people with Down's Syndrome (without a dementia diagnosis) in a sample of 25 (Shanahan, 2014), which found improved cognition at a three month follow up. There is currently no known randomised controlled trial (RCT) for group CST with individuals who have ID and dementia.

Despite the recommendation of CST for dementia by NICE [NG97], there is only one published feasibility RCT assessing the impact of a psychosocial intervention for people with ID and dementia (Ali et al., 2022). They assessed feasibility and acceptability of individualised CST (iCST) in a sample of 40 individuals with dementia and ID, concluding that iCST was feasible and acceptable. The RCT also found improved quality of life at a 21-week follow up, with no changes in adaptive functioning or cognition. There were also no significant changes for paid and family carer measures (caregiver burden, sense of competence and anxiety or depression symptoms). Four paid carers and two family carers were interviewed. The qualitative findings highlighted that the iCST set up process (e.g. training for carers to deliver the intervention) was positive and the intervention itself supported carers in developing a helpful perspective of the person they were caring for. However, some barriers were identified, where some activities were unsuitable for individual needs or cognitive ability. Similarly, participant motivation or mood seemed to be a key barrier. Carers also struggled to fit the requirements of the iCST within their busy work schedules.

Ali et al. (2022) raised some concerns that group CST with this population may not be as amenable to adaptation as personalisation is often required in interventions for people with ID. In line with the use of individualised CST, Ali et al. (2022) included carefully considered adaptations to CST activities, previously piloted in five people with dementia and ID (Ali et al., 2018). However, due to the concerns noted by Ali et al.

(2022) regarding carer time to deliver the intervention, additional workload required for the level of personalisation and poor fidelity (e.g. carers did not follow the required session structure) in iCST as potential barriers, group CST could mitigate some of these barriers. In addition, group CST is the NICE recommended option for people with dementia [NG97], and thus should at the very least, be trialled for people with ID, rather than exclude them on the basis that they may not be able to access this group intervention.

Aims and Relevant Definitions

The current study aims to qualitatively explore the experiences of an adapted version of group CST for people with ID and dementia (CST-IDD). Exploration will focus on the acceptability and feasibility of CST-IDD with group participants, their carers and group facilitators.

Acceptability will be determined by any factor which indicates how the intervention is received by group participants, facilitators, and carers. For example, if unacceptable, there will be a general experience of poor attendance with no other explanation for non-attendance. If the group is perceived to have positive consequences, then the intervention will be more acceptable.

Feasibility will be defined by any factor which impacts the ability to successfully facilitate (facilitators), attend and participate (group participants) or provide care/support for group participants (carers) within the group. Factors which influence whether the group is practical and possible to run for individuals with ID and dementia will be discussed in terms of feasibility, where extensive factors for consideration will decrease overall feasibility.

Research Question

How acceptable and feasible is an adapted CST group for people with ID and dementia from the perspective of people with ID&D, their carers and group facilitators?

Important note: The phrase, ‘people with ID&D’ will describe the CST-IDD group participants who took part in qualitative interviews. ‘Interview participants’ are those who took part in qualitative interviews (people with ID&D, some carers and some facilitators). ‘Participant’ or ‘group participant’ will be used to refer to all individuals who took part in the CST-IDD groups.

Method

This study was part of an NIHR funded RCT to assess the feasibility and acceptability of group CST for people with ID and dementia compared to treatment as usual (TAU), using a mixed methods design (Ali et al., 2023). For the RCT, learning disability teams were approached across six National Health Service (NHS) trusts in the UK. Health professionals from each team approached and provided an accessible information sheet for possible participants and gained consent to be contacted by the research team. A research assistant met with the potential participant and their carer and obtained informed consent, or where they lacked capacity, a friend or a relative (personal consultee) was asked to sign a declaration form agreeing to their participation. If a personal consultee was not available, a clinician not involved in the study (nominated consultee), was approached and completed the declaration form. Potential participants resided in a variety of settings including supported living, residential and family homes. They were recruited for the RCT from their local learning disability service as per the inclusion and exclusion criteria outlined below.

Inclusion criteria:

1. Premorbid mild or moderate ID (based on clinical notes)

2. Aged 18 and over
3. ICD-10 diagnosis of mild or moderate dementia
4. Able to provide informed consent or where the participant lacked capacity, he/she had a personal consultee who had agreed to the potential participant taking part in the study.
5. To be able to communicate in English

Exclusion criteria:

1. Severe ID, preventing engagement in CST groups
2. Severe or late-stage dementia
3. Had a visual impairment or hearing impairment that may interfere with the participation.
4. Had significant physical illness or disability preventing their participation
5. Had significant behavioural problems that could affect participation (e.g. aggressive behaviour)

Participants receiving anticholinesterase inhibitors as part of their usual treatment were not excluded.

Individuals with dementia and ID who were recruited to the RCT were randomised to receive either 14 sessions of group CST (over seven weeks) or TAU. There were 18 participants in the CST arm and 16 in the TAU arm. However, two participants allocated to CST did not receive the intervention. The original CST manual recommended that the 14 sessions be run as two sessions per week on two different days. However, all groups opted to have both sessions in the same day. There were three to five participants per group. Paid or family carers also attended the groups. There was no recommendation for carers to remain within the group sessions, but all groups opted for carers to stay in the group when available. Each group was facilitated by a minimum of two trained facilitators who were from a range of different professions including occupational therapy, nursing, psychiatry and psychology. Facilitators received one day of standard CST training with an additional two-hour session on CST-IDD adaptations. Additional facilitators were trained per site and some sites were not consistently facilitated by the same staff member due limited staff availability.

One site was unable to recruit, thus all participants were recruited from five out of the six Learning Disability teams. Due to inadequate numbers of eligible participants within each team, four intervention groups were run across five teams. In terms of adherence in delivering all sessions, one group delivered 12, one group delivered 13 and two delivered all 14 sessions.

The group CST intervention followed the original CST manual (Spector et al., 2020) augmented with supplementary information containing recommended adaptations for people with ID and dementia (e.g. using pictures rather than words for certain tasks). The CST-IDD supplement was developed as part of the wider trial to be used alongside the original CST manual with input from various stakeholders, including carers, professionals and individuals with ID. Various resources were also provided, such as bean bags and pretend money (a full list is included in Appendix C).

Interview participants

All group participants and carers who had attended the adapted CST groups, and group facilitators were eligible for participation in qualitative interviews. Group participants were eligible if available on the day of one of the final two sessions and re-consented to a short interview (up to 30 minutes). Carers and facilitators were contacted outside of the group via telephone or email.

Design and procedure

Qualitative data were collected via semi-structured interviews. All interviews were transcribed shortly after each session.

Interview schedules

The interview schedules were developed and refined by the research team. Interview questions (see Table 1) were developed with reference to the acceptability and feasibility aims. These questions were then discussed with professionals with expertise in CST and interventions for individuals with ID. The schedules were also discussed with a service user panel of individuals with ID and their carers.

AAC methods were incorporated into interview schedules for people with ID&D. The Talking Mat methodology was decided on as it has been proven to be effective for individuals who have a basic level of communication, which was a pre-requisite of recruitment for the RCT. The topic of discussion (CST-IDD) was decided at the start of the interview and the individual was provided with various images for each question. Open question such as 'what did you think about having your carer *carer name* in the group' were used. The current study used the scale 'Like', 'Unsure' and 'Don't Like', where the person with ID&D would place the image on the scale by their preferred option.

Interviews also included a shorter validation exercise to determine whether the group participant would be able to engage with the Talking Mat methodology. This exercise included a simpler version of the interview schedule questions and asked the individual to sort whether a picture (e.g. a car) was something that they could eat, not eat or whether they were unsure about the item. See Appendix I full interview schedules and validation exercise, alongside the schedules for carers and facilitators (Appendices J-K).

The key interview questions (for people with ID&D, carers and facilitators) relating to the current acceptability and feasibility aims are presented in Table 1.

Table 1

Interview questions

People with ID&D	**Carers**	**Facilitators**
How did you feel about… The group quiz/ _________________that you did today in the __________ group? The other activities that you have done in the __________ group? Being in a group setting? The support you got from ____________ and __________ the group leaders? Your carer ____________ being/not being in the __________ group? The _________ group sessions were _______ long. How did you feel about the length of the __________ group sessions? How did you feel about going to the __________ group twice a week? Having breaks half way through the __________ group sessions? Talking about your experiences and ideas in the __________ group?	How did you come to be involved with this research and the CST group	How did you find facilitating the CST group? - What do you think contributed to that? - Did you know the participants before the group? How do you think the group participants and their carers found the CST group? - What do you think contributed to that?
	What were your initial expectations of the group?	Were there any sessions that went well or not so well? Or any sessions that participants enjoyed or participated in more or less? - Why do you think that was? What did you think of the practical arrangements of the group? For example, the length of session, having two sessions a week, the group size, whether there were carers present etc? How did you find the manual and supplement? - What were the good and bad bits about it?
	How did you and the person you care for find the CST group? - What do you think contributed to that? - If need prompts: ➢ What did you like/dislike? What about the person you care for?	In your opinion were there any positive or negative impacts of the group for participants and/or carers? - What do you think contributed to that?

Hearing about other people's experiences and ideas in the __________ group?	➢ Where there any aspects that the person you care for engaged in more or less?	
	What positive or negative impacts has the group had for you or the person you care for? - What do you think contributed to that? Is there anything that you would change about the CST group if it was to be run again? Is there anything else that you would like to say about the CST group? - Prompts for the end if haven't covered any of these topics: ➢ Any comments on specific sessions, format of the sessions (set up/frequency/length/group or session number)?	If you were to run this group again, what would change? Is there anything else that you would like to say about the CST group or your experiences of running it?
Is there anything else that we have missed that you would like to say about the __________ group? Is there anything you would like to change?		

People with ID&D

Interviews were carried out in person (in the session break or at the end of the sessions) to maximise recall for details of the group. The person with ID&D was provided with an easy-read information sheet about the interview process and interviewer (Appendix D). Their consent to continue with the interview was checked and a discussion was had about how they might signal that they no longer wish to participate in the interview (e.g. holding their hand up, leaving the room). Once agreed, the semi-structured interview schedule was used alongside the Talking Mat methodology described above. At the end of each interview, they were given the opportunity to add further comments or amend their Talking Mat.

The Talking Mat validation exercise was completed where possible, but the main interview was prioritised when individuals had other commitments (e.g. pre-booked taxi). Few individuals responded to all questions, and as such, a flexible interview approach was taken. Three out of the five people with ID&D who were interviewed were able to engage for the entire interview. These interviews were voice recorded. At times, people with ID&D did not verbally express a response (e.g. ‘nodding’) and the researcher recorded any key non-verbal communications. These non-verbal communications were added into the transcript.

Facilitators and carers

Carer and facilitator interviews (up to 1 hour) took place remotely and were recorded via Microsoft Teams. Facilitators and carers were provided with an information sheet and consent form prior to participation (see Appendices E-H). Verbal consent was checked at the start of the interview. The interview schedules for facilitators (see Appendix K) and carers (see Appendix J) were applied in a semi-structured format. Similarly, if some questions did not apply, these were missed or re-worded as required.

Data Analysis

Facilitators and carers

A thematic analysis was used to analyse data from facilitator and carer interviews. The analysis method is drawn from methodology described by Fereday and Muir-Cochrane (2006) combining the use of an inductive (Boyatzis, 1998) and deductive coding approach (Crabtree & Miller, 1999). Interviews were semi-structured, where existing questions were informed by the research questions , thus allowing for a pre-existing a priori codebook (Table 2) alongside a posteriori codes from the data.

The a priori codebook for facilitator and carer interviews was informed by the interview schedule and overarching themes were informed by the research questions (see Table 2). A posterior codes will be reported in the results section.

There has been little consensus on the difference between a ‘theme’ and a ‘code’ within the literature (Fereday & Muir-Cochrane, 2006; Boyatzis, 1998), thus the current analysis will refer to themes as overarching and related to the research question, whereas individual codes will refer to factors within each theme.

A step-by-step guide by Swain (2018) describes the methodology by Fereday and Muir-Cochrane (2006) in further detail and as such, was used as a guide (see Figure 1). Although the analysis utilised a step-by-step approach, these stages did not occur in a linear fashion, but the process was iterative and flexible. A Microsoft Word document was used to organise and code the data.

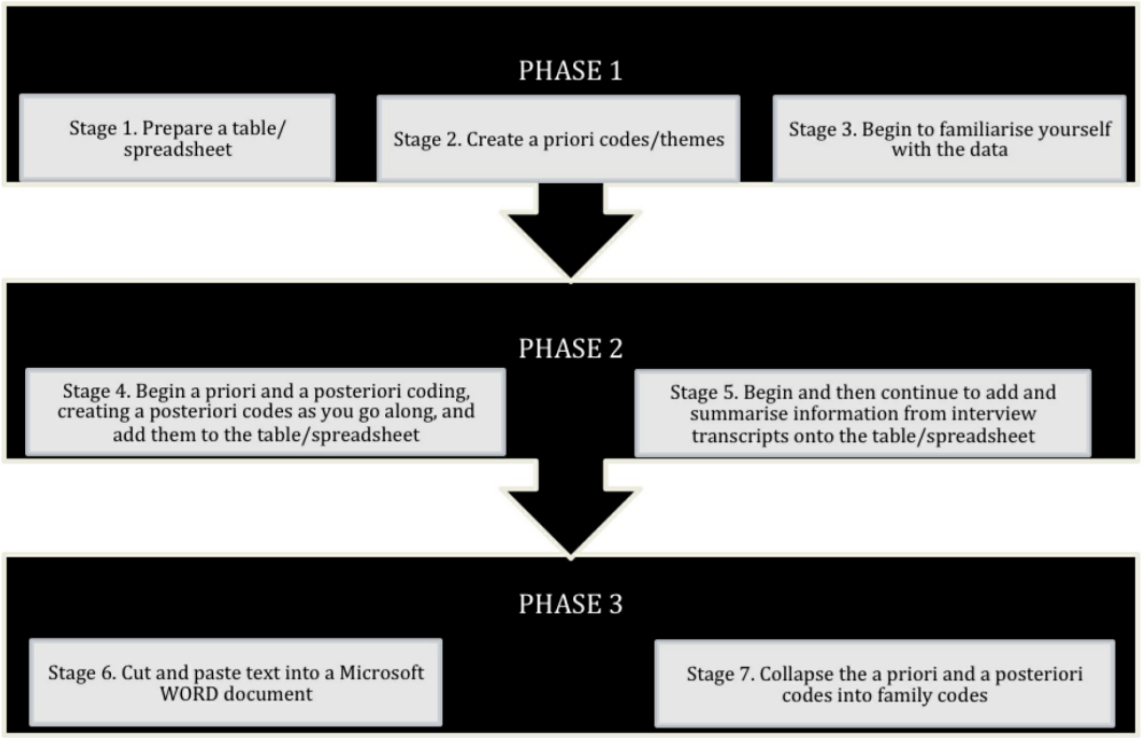
Table 2

A priori codebook for facilitator and carer interviews

THEMES	A priori codebook	Description
ACCEPTABILITY	**Expectations**	What was expected and did the group meet/exceed these.
	Attendance	Regular, consistent attendance by participants would indicate acceptability.
	Perceived consequences	What were the perceived consequences (positive/negative/no consequences) for participants, facilitators and/or carers.
FEASIBILITY	**Enablers**	What factors improved facilitation of the group (facilitators), attendance and group participation (participants) and ability to care for/support group participants (carers)
	Barriers	What factor hindered facilitation of the group (facilitators), attendance and group participation (participants) and ability to care for/support group participants (carers) .

Figure 1

Stages of inductive and deductive thematic analysis from Swain (2018), original methodology by Fereday and Muir-Cochrane (2006).



Note. Figure reprinted with permission from Swain (2018, p.10)

People with ID&D

Interview data from people with ID&D were analysed using a content analysis, as the responses relating to each aspect of the group were often categorial (e.g. ‘Like’, ‘Unsure’ or ‘Don’t Like’). As such, responses could only be counted rather than analysed in thematic detail. Pictures of each individual’s Talking Mat will be displayed in the results section. For people with ID&D, content analysis categories were directly informed by each interview question (Table 7).

Researcher position

It is important to capture the researcher's identity as the analysis, although somewhat deductive, will be influenced by the researcher's characteristics and experience (Swain, 2018). To minimise potential biases, all stages of the qualitative analyses were overseen by the qualitative lead for the trial.

The researcher is a female trainee clinical psychologist in her late 20's, of South Asian ethnicity. She has some experience working within an Older Adult Mental Health Service and Memory Clinic, but limited experience working with individuals who have ID. This reflexivity statement will be expanded upon in part three of the thesis.

This study was a joint project with another trainee psychologist (see Appendix M for further details).

Ethics

The study has been approved by the Health Research Authority and has also been given ethical approval by East of England - Essex Research Ethics Committee (REC reference number: 21/EE/02/47; Appendix L).

Findings

Interview participant characteristics

Although 16 participants were randomised to receive the adapted CST intervention, only eight attended sessions 13 and 14, of whom five were interviewed. Reasons for session 13 or 14 group participants not being part of the interviews included: no re-consent (n = 1); unable to engage with interview content (n = 2). Only one facilitator out of ten was not interviewed as they did not respond to email correspondence. Of carers who were not interviewed (*n* = 9), various reasons were recorded for non-participation including: feeling they had nothing to add as the group participants they supported did not attend consistently (*n* = 2), did not want to sign the consent form (*n* = 1), did not follow up on calls or emails (*n* = 2) were not approached for a qualitative interview due to final session cancellation (*n* = 3) or did not attend and the interview session could not be rescheduled (*n* = 1).

Table 3 details the number of people with ID&D, facilitators and carers who agreed to be interviewed. To preserve site confidentiality, each NHS trust is given a number from 1-5 and each CST group is given a letter code from A-D. A total of 20 qualitative interviews were completed.

Demographic information was collected for the RCT rather than specifically for use within the qualitative arm. Group participants who were allocated to the intervention condition had a mean age of 63.12 (*n* = 17) and their carers had a mean age of 47.14 (*n* = 14) at baseline. Seven participants were diagnosed with a mild ID (43.8%) and nine were diagnosed with a moderate ID (56.3%). Most participants lived in 24 hour supported housing (*n* = 12; 75.0%). Others lived with a relative (n = 1), in part time supported housing (n = 1) and in a nursing home (n = 1). Carer demographics were collected as part of the RCT, however different carers accompanied group participants to each session and to each data collection appointment. At baseline, most carers were support workers (*n* = 6; 46.2%), followed by paid carers (*n* = 3; 23.1%), key workers (*n* = 3; 23.1%), and one family carer (*n* = 1; 7.7%). Additional demographics at baseline for group participants and their carers are displayed in Table 4. For group facilitators, this information was not collected as part of the RCT or the qualitative interview process.

Table 3

People with ID&D, facilitators and carers per CST group who completed a qualitative interview

CST Group	A (1)	B (2)	C (3)	D (4 and 5)	Total
People with ID&D	1 / 4	1 / 4	0 / 3	3 / 5	5 / 16
Facilitators	3 / 3	2 / 2	1 / 2	3 / 3	9 / 10
Carers	3 / 4	1 / 4	0 / 3	2 / 5	6 / 16

Note. letters denote group; numbers denote Trust

Table 4

Demographic information at baseline for group participants allocated to the intervention condition and their carers.

Characteristic	Participants (N = 18)	Carers (N = 14)
	Gender	
Male	12 (66.7%)	4 (28.6%)
Female	6 (33.3%)	10 (71.4%)
Prefer not to say	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)
	Ethnicity	
English/Welsh/Scottish/Northern Irish/British	15 (83.3%)	8 (57.1%)
Irish	1 (5.6%)	0 (0%)
Gypsy or Irish Traveller	0 (0%)	0 (0%)
Any other White background	0 (0%)	2 (14.3%)
White and Black Caribbean	0 (0%)	0 (0%)
White and Black African	0 (0%)	0 (0%)
White and Asian	0 (0%)	0 (0%)
Any other Mixed/Multiple ethnic background	1 (5.6%)	0 (0%)
Indian	0 (0%)	0 (0%)
Pakistani	0 (0%)	0 (0%)
Bangladeshi	0 (0%)	0 (0%)
Chinese	0 (0%)	1 (7.1%)
Any other Asian background	1 (5.6%)	2 (14.3%)
African	0 (0%)	1 (7.1%)
Caribbean	0 (0%)	0 (0%)
Any other Black/Caribbean background	0 (0%)	0 (0%)
Arab	0 (0%)	0 (0%)
Any other ethnic group	0 (0%)	0 (0%)

A posterior codes

Further a posteriori codes (Table 5) were developed from the facilitator and carer interview analyses. These were subdivided where applicable by: 1) group delivery, 2) practical considerations and 3) CST content. There were no a posterior codes for expectations and attendance.

Table 5

A posterior codes for facilitator and carer interviews

A priori codebook	A posteriori codes					
Perceived consequences	Positive					
	Negative					
	Neutral					
Enablers	**1) Group delivery**					
	Facilitators	Social interaction/connection				
	2) Practical consideration					
	Carer support	Distance /travel	Group size	Individual differences	Resources	
	Session/day structure	Autonomy/mastery	Set up			
	3) CST content					
	Activities/sessions					
Barriers	**1) Group delivery**					
	Facilitators	Social interaction/connection				
	2) Practical considerations					
	Carer support	Distance /travel	Group size	Individual differences	Resources	Session/ day structure
	Fatigue/tiredness	External environment	Competing demands	Site/venue	Set up	
	3) CST content					
	Activities/sessions					

Carer and Facilitator Interviews

Acceptability

Expectations.

Carers were often unsure of what to expect, expected the group to be generally helpful or reported that some expectations were unmet.

"I think we were expecting also maybe there would be interaction between the doctor and the clients…" (CARE04).

Attendance.

Only one group (Group D) had consistent attendance and suitable notice for non-attendance (medical appointment and cold weather). Facilitators from other groups commented on inconsistent attendance (one to two participants) due to a variety of reasons (captured by the a priori code 'barriers', where some examples were: felt anxious in the group, long travel, health issues, not brought by carers or too tired). However, in some instances no barrier was indicated. Facilitators for one group also postponed some sessions due to poor attendance.

"…two participants did not turn up. One was because of the increased anxiety so couldn't cope with this group sessions. Another participant is far from where he lives…because it's quite far to commute…" (FAC07)

Perceived consequences.

Positive.

A wide range of positive perceive consequences for participants were shared, some of which were short-lived session by session (e.g. engaging with each other, excitement to attend and enjoyment in activities).

“One session where we had a snakes and ladders that we played like that was the amount of joy that was in that group was massive…that was the cherry on the cake, to be honest.” (FAC03)

A number of positive consequences were also noted outside of group sessions for some participants including: better recollection of long-term memories (e.g. childhood session), slower deterioration, memory for details about the group (e.g. facilitator name, group song) and/or general improvements outside of the group setting (e.g. memory, communication and sleep).

“But the more she did these activities, even obviously at home, I've noticed that she's straight away on point, responding quickly rather than you talking to her and she'll sit there and, like, look around and I can see she's processing what you said so she knows what to repeat back, but no, she's straight away like I think it has helped with her, like memory a bit like, you know, she's kind of gained more like communication skills really.” (CARE03)

Carers and facilitators also noted some positive consequences for themselves, including: enjoyment, meaningful work and learning more about dementia. One carer felt better equipped to understand the participant and notice any changes to their abilities. A thoughtful consideration to provide sugar free biscuits during the break allowed one carer some respite in monitoring a participant’s sugar intake. Another facilitator commented on rapport and mutual enjoyment of the interactions between participants and facilitators.

“And what was meaningful, which was lovely because we were just there listening…. Really lovely memories for them, which was lovely as facilitators to kind of hear.” (FAC01)

One facilitator shared an overall positive experience of sessions and general benefits to the service.

"For me personally, it is very productive. I think it is beneficial for the participants as well as for the service." (FAC07)

Negative.

Some perceived negative consequences could be framed as a positive, where some participants were observed to feel sad that the group was coming to an end. The group appeared to be beneficial for these participants, but the limited number of sessions may have negatively impacted the consistent routine and structure often required for people with dementia and ID.

"…that one person and again towards the end of session when we talked about ending, you could see sadness because I think he really did like that peer support that consistency, he knew what was happening for the next seven weeks. So it was like in a routine structure." (FAC01)

Other perceived negative consequences that were caused by the group were: tiredness due to two back-to-back sessions, sadness after a topic of discussion (e.g. the royal family and the queen had recently died, difficult events in childhood) and increased anxiety in a new setting.

"I think when we were talking about the royal, about the queen and then she became tearful…Right. I believe that was something that reminded her of the Queen, who had passed away…" (FAC04)

In terms of individual experiences, one participant wanted to leave the room and his carer noted that he would pretend to feel unwell (e.g. pretending to be sick or have a heart attack) to let his carers know he did not want to stay. This person did not attend after the first session. Some carers were concerned that some behaviours related to participant frustration may have negatively impacted other group participants. One participant was observed to decline in ability, and one facilitator speculated that this may have been due to the natural progression of their dementia, or an unknown factor related to the group. One carer was described as very critical and despite intervention from facilitators, may have resulted in a negative experience for this participant.

“It actually frustrated XParticipantX…I wondered whether she would have done much better if her XCarerX wasn't there” (FAC06)

Facilitators reported experiencing perceived negative consequences for themselves including personal frustration and wasted clinical time. The reasons for the frustration and wasted clinical time will be described further by the a prior code ‘barriers’.

“so that was a bit frustrating because it's quite a lot of effort for one person.” (FAC02)

Facilitators did speculate on negative consequences that carers may have experienced. Carers may have struggled with having little information regarding their role within the group (e.g. when to step back and when to step in and help). Carer motivation was observed to wane as they may have not noticed any lasting benefits for participants. Some carers may have struggled to commit to attending all sessions. In addition, the time spent by carers to bring someone to the group, including travel may have resulted in some negative consequences. On one instance, when a carer did not attend, the participant did not attend, suggesting that a good carer-participant relationship is helpful but not when one person in the dyad cannot attend.

“I just don’t think they kind of got what CST was about….and how…what it is that we were doing would benefit the individuals because …this is only my views obviously, but it could be seen from an outsider looking in, that basically we're just playing games and actually there's no meaningfulness behind what we're doing.” (FAC09)

Neutral.

Some carers shared that although the group resulted in some enjoyment, there were no changes outside of the group session, for example, in cognition or mood. One carer shared that their participant was unable to recall having been to the group. Another participant fell asleep in many sessions, where having two sessions in one day may have limited potential benefits due to increased fatigue.

“Because I'm sure before we even got home, she kind of forgot about the session.” (CARE05)

Feasibility

Enablers and Barriers.

Group delivery.

Two a posteriori codes were developed from the data: facilitators and social interaction/connection.

Facilitator skill in both implementing the adaptations from the CST-IDD supplement and using additional adaptations, supported participation in sessions. Facilitators described some adaptations from the CST-IDD supplement: personalising sessions to participant interests, enlarging the symbols/pictures provided, simplifying activities (e.g. word association to picture association), reducing the number of activities (from two per session to one) and a poster prompt with the group name.

“so we had to make a lot of reasonable adjustments around simplifying that and making the activities accessible as possible.” (FAC09)

Additional adaptations that were made included: incorporating sensory activities (e.g. using play doh), using movement as part of the theme song (e.g. encouraging dancing), including an active break, adjusting the seating plan as required and moving the break to the end.

“…so we were making sure that…they are spaced… within the room…there was one with…hearing issues…we were making sure that she's… sitting right close to us…” (FAC03)

Two specific adaptations involved swapping fine motor activities (e.g. cards and small bingo pieces) to a gross motor or sensory alternative, such as using air dry clay (resource not provided), bowling and throwing beanbags.

“Yeah, we didn't do some of the games like bingo…or the card playing because we thought that the… resources that were provided were very small for them to handle.” (FAC03)

Some key skills related to the facilitator’s profession, for example, one facilitator appreciated their co-facilitator’s occupational therapy experience in adapting resources. Another facilitator noted the skill required to support a particular participant when they noticed that the carer was not being supportive.

“…I've seen how you know, they interact with her and she is able to understand on her basis and how they can help with her.” (CARE03)

One particular group had more than the recommended minimum of two facilitators. They found that when this dropped to two due to unforeseen absences, it was difficult to facilitate. A facilitator staffing switch was also described as a barrier.

“…find it trickier. When there was only two of us.” (FAC06)

In addition, consistent facilitators appeared to be useful for some facilitators in organising sessions. Therefore, facilitators were a key enabler in terms of delivering an adapted group for participant needs and requirements.

‘Social interaction/connection’ as a code was often discussed as an ethos across all sessions, i.e. delivering groups with social connection in mind rather than a singular technique. The interactions between participants were noted as important in setting up a positive experience. Interactions between group participants were often encouraged (e.g. amending the seating plan to facilitate interactions). Although the CST-IDD supplement did not explicitly state encouraging interactions, there is a similar embedded ethos in encouraging interactions between group participants for various activities (e.g. encourage playing instruments together).

“…you know you can help them to explore things…It's a friendly, approachable like safe space, isn't it? For them to explore and learn and think about the world and make connections…And being somewhere social” (FAC02)

“…because then we got social interaction amongst the three individuals which was lovely to see and it was like this is how we need to kind of try to plan… our sitting…” (FAC09)

Good relationships between carers and participants were key in enabling participation and improving relationships between facilitators and participants with each session may have increased engagement for group participants.

“And I think what was lovely us that more than often and is that we saw….change in terms of rapport with us but also just a bit more of the participant and you can really see that they really enjoyed and they engaged well with it…” (FAC01).

Social interaction/connection therefore acted as a barrier when absent, especially with inconsistent attendance (e.g. one participant). Two participants lived in the same home, and solely attended together, suggesting that their existing connection was a barrier to forming new connections.

"…he's just missing the interactions from the other individuals…" (FAC09)

In terms of social interaction/connection as a further barrier, there was also a general lack of familiarity between group participants and facilitators. Time limitations prevented familiarisation with group participant notes. One facilitator shared that the lack of familiarity led to 'one of the biggest challenges'.

"….one of the biggest challenges not knowing the people who come to the group because we haven't been able to meet them before. I think with hindsight, even just one meeting with them could have been helpful" (FAC06)

Practical considerations.

Carer support was noted to be a core enabler by almost all facilitators. Carers paid attention to unique needs and supported with maximising participation. For example, one carer provided personalised instruction as the group participant struggled with hearing loss which helped facilitators to focus on the wider group. Carers reported these key skills within their interviews, including: encouraging participation, providing 1:1 attention, sharing carer expectations with colleagues (e.g. enable independence), clarifying confusion (e.g. that the break is not the ending) and providing incentive to keep focus (e.g. promising a nice lunch).

"So we have to do together with XParticipantX to encourage him to show like this is I'm doing like this now so you can follow me and then XParticipantX was able to participate with some of the activities." (CARE04)

Therefore, a lack of suitable carer support, was a significant barrier. For example, a new carer struggled to find the group location and the participant was unable to join. Carers found it difficult to step back, as they were often used to supporting with all care needs. Additionally, carers reported that due to funding cuts, there were limitations in carer availability.

“Normally as a service, If I hadn't been there as an extra person, we wouldn't have been able to get him there because we support four people and it sort of impacts on all of them as well.” (CARE02)

Facilitators shared that with limited carer support (e.g. did not stay to support with taking the participant to the bathroom’), facilitation was difficult. Facilitators also commented on other carer support barriers including: carer shortages impacting consistent attendance, variable carer skill and carer disengagement from the group.

“…They left and then came back, so his carers weren't there. So I think, you know, perhaps it's helpful for the carers to hang around in the building.” (FAC02)

Facilitators shared some difficulties with individual carers. One group participant did not join the group when a particular carer was not on shift and another carer was quite difficult to manage in the group (e.g. responded on behalf of the person they were caring for).

“So trying to get XCarerX to to give some space and not respond, it's probably a much bigger… clinical intervention than we were able to manage and to model…”(FAC06)

‘Distance/travel’ was an enabler for participants when the distance was convenient but was a barrier to both consistent attendance and having a positive experience when inconvenient (e.g. toilet breaks on a long journey).

“…so even though we took him to the toilet….it was over 40 minutes trip due to the traffic. So on the way back he was telling us he was bursting. He needs to use the toilet. So the transport was bit long for XParticipantX” (CARE04)

Some facilitators experienced distance as a significant barrier themselves. As a result, two sessions per week were often run in the same day creating further issues (see code ‘fatigue/tiredness’).

“…for me, I was coming from XLocationX…So a lot of clinical time was taken away…” (FAC03)

‘Group size’ was both a barrier and an enabler. Facilitators felt that few group participants (one to two) led to limited interactions, but too many, limited 1:1 attention. However, carers preferred a smaller group.

“But when we add four, it felt a bit much and obviously when we had one well, that's not really a group.” (FAC05)

“

Many individual differences were discussed as barriers and enablers, highlighting that despite the best set up, individual characteristics impacted feasibility. Some examples of barriers were ill-health or dementia progression, overwhelm in a group space (this participant moved to their own space) and poor hearing (no hearing aid provided). Some enablers were: enthusiastic group participants, some intact memory skills to be able to remember some details from the group and personal preferences for certain activities.

‘Resources’ were solely discussed by facilitators, as carers had little involvement with resource developments. The CST-IDD supplement (rather than the original CST manual) provided helpful suggestions. However, some resources (images and physical items) were unsuitable, requiring adaptation (often enlarging).

Although the supplement suggests enlarging some of the images provided, facilitators shared that the time required to do so led to a significant barrier to facilitation time. In addition, some physical items (e.g. bingo pieces) were also too small to use for some participant needs.

"…those pictures weren't going to be any use to our clients. They were very small, not clear, so had to spend a considerable amount of time developing visuals for each session" (FAC08)

Individual circumstances were also raised by facilitators as a barrier, who shared that some participants did not have a risk assessment, personal leave left little time to prepare, and IT issues led to difficulties in accessing some resources. One carer felt that the person they supported did not have enough information about the group prior to attending. The sessions were too long for this participant, and they stopped attending, suggesting that with further information, someone else could have benefitted from the group.

"…not very clear from the letter you had to kind of go to the session to know… what it was like." (CARE05)

With the 'session day/structure', participants were reported to engage better early in the morning for some groups and late morning for others. Participants seemed to benefit from the routine of attending weekly sessions. However, all groups opted to have both sessions in one day for carer and facilitator convenience, but this was often too long for participants where the code 'tiredness/fatigue' was mostly discussed in relation to session length.

“…they were quite involved, especially during the first one… Some of the clients were getting, like quite bored in the second one…doing 2 on the same day and it was too much for them…” (FAC03)

Surprisingly, session breaks were a barrier for various reasons including: too many breaks, some participants confused the break with lunch/ending and others lost interest after a break.

“…Then after the coffee break did not feel she wanted to stay and she keep on asking to go…” (FAC04)

‘Autonomy/mastery’ was solely described as an enabling factor. Group participants appeared to engage with the session when given choice and control in choosing the best group name/song and when they identified correct answers. It is useful to note that CST principles aim to not focus on correct answers to avoid disappointment, but individuals still benefitted from a sense of mastery.

“…giving the participants control as to…what the group name was and what song they wanted because it came from some and interest them.” (FAC01)

‘Competing demands’ were a barrier for some, as the group was out of the participants’ usual routine, they may have required additional reminders on the day. One participant had clashing social activities, and another had an activity just before the session and was too fatigued to participate fully.

“I mean the first, because she goes to XActivity NameX obviously she stopped that to come to this. So at the start it we had to keep reminding her in a way to say, you know, you're not going to XActivity NameX, you're going to the CST…” (CARE03)

The ‘external environment’ was a problem during extreme heat; therefore, one group was rescheduled to winter. However, sessions in the winter led to other barriers for travelling (e.g. snow, dark and cold).

“And then again when we had the severe heatwave and given that they're vulnerable…it a Class 4 basically saying that vulnerable people should avoid heat and not go out so it got pushed to December but then that's when we had snow.” (FAC01)

Facilitators raised concerns about the ‘site/venue’. Some facilitators did not have full access to buildings and struggled to organise break refreshments, parking, bathroom facilities and/or find a suitable room.

The code ‘set up’, related to having a better setup available, leading to improved feasibility in facilitating CST-IDD. These included: protected time to prepare, set up ready to go by the research team (e.g. recruitment) and information about participants.

“Useful to not have to do the kind of the pre meeting and the logistics in some ways that was taken care of by the research team” (FAC06)

Therefore, a poorer setup was a barrier to facilitation. The following set up issues impeded session planning and included: a last-minute rush to start the group, resources not prepared and no access to some participant notes. Facilitators commented on delays to the group start date, leading to a lag between their CST training and application. One facilitator speculated that participants who were identified as suitable may no longer have been, due to dementia progression with an increased wait period.

“…those individuals were maybe not at the stage they were when they come to the group. So I think possibly because of some of the delays in terms of having everything prepared and ready…kind of contributed to bit to their decline” (FAC09)

CST content.

Some general barriers shared across activities were: conversational tasks based too heavily on verbal communication, ‘sit down’ activities and tasks which were ‘too easy’ or ‘too difficult’ for participants.

In addition, one carer noted that the homework task was not suitable, which was not a CST-IDD requirement, but an adaptation made by facilitators of that group which was not in adherence with the supplement. The carer shared that they did not collect newspaper articles for the current affairs session as requested, as the participant may have struggled to read about some difficult news events.

A list of enablers and barriers in relation to specific sessions are displayed in Table 6.

Table 6

Sessions and activities which were enablers and barriers.

Enablers	Barriers
Sessions	
Childhood	Categories
Food	Word games (e.g. ‘going to the market game’)
Faces and scenes (completely tailored to one participant’s interests)	Food
Current affairs (adapted easy version)	Money
Word association (replaced with pictures or simpler options)	Quiz
Sound	Current affairs
Money	
Orientation (included the local area)	
Categories (adapted version)	
Activities	
Active games: bowling, snakes and ladders, beanbags, bingo (adapted	Card making

version without smaller pieces)
Singing
Crafts (e.g. collaging)
Group song
Music
Play doh

Tasks which required word skills were often deemed too complex (e.g. word association) unless adapted to a simpler version (e.g. picture association) as suggested by the CST-IDD supplement. Many word skill sessions relied on some of the CST-IDD supplement modifications to improve engagement.

Enablers were active games that did not require fine motor or word skills (e.g. bowling, throwing beanbags). Participants enjoyed sessions with tangible resources, including the music session (with musical instruments) and the childhood session (with photographs).

The session on money was enjoyable for some groups, and too complex for others, highlighting the variability in daily living skills. In addition, one facilitator noted how money has changed in recent years, influencing the relevance of included resources (e.g. pretend money).

The food session raised some risks with using real food (e.g. dysphagia), and the resources provided some play food. However, some of the labelling was too small or play food was too abstract for some participants. However, for those who could engage with the play food, this session appeared to be engaging.

Recommendations

Recommendations for future groups was included as an interview question for facilitators and carers. However, these were not coded as this question does not directly relate to the key research questions. A summary table of these recommendations is included in the discussion section (see Table 8).

People with ID&D

As responses from people with ID&D were often brief (e.g. nodding or yes/no), quotes are only used where individuals have expressed a phrase, rather than reporting a quote for each category. Table 7 summarises individual responses and each Talking Mat is displayed in Figure 2. As some people with ID&D did not respond to questions or were unable to complete the full interview, complete responses are not available. Key considerations for each interview have been recorded in Table 7 to provide additional context. For example, PPT05 had a very brief interview as they appeared to become distressed, and their responses may not be a true reflection of their experience of the group. However, this interview was included, as PPT05's contribution to the interview provided valuable information on what they enjoyed during the group (e.g. bowling).

People with ID&D generally had a positive experience of the pre-interview activity (money, bingo, word games and bowling). They liked being in a group with carer and facilitator support.

"I like being with people." (PPT02)

"It's been you know really good with meet…meeting different people" (PPT03)

"Very kind." (PPT02; about facilitators)

The response to session length was mostly positive, but one person with ID&D expressed it was too long and one individual was unsure.

"it's is…long." (PPT04)

The individual who did not like the number of sessions shared that this was because they would have liked more sessions.

“If if I could come in…more often.” (PPT03)

Of the people with ID&D who responded, all individuals chose ‘like’ for: having a break in the middle, the group song and talking about their own experiences.

*“I like *humming tune*” (PPT05)*

One person with ID&D said they did like hearing others’ experiences, but then placed the card under the ‘don’t like’ option. All others did enjoy hearing others’ experiences. However, not all individuals got along with each other, and PPT02 shared that they did not get along with one other participant.

“I I do like people talking about different things.” (PPT03)

“Well, that XGroup Member NameX girl, she’s…she’s alright but she goes…she does my head in” (PPT02)

One person with ID&D was particularly enthusiastic about their friend joining the group.

“if we could… if we could get a couple, probably not now but when we have the next session could we have some new people join us?” (PPT03)

“… cause I’ve got another guy with this in the same house as me…He would love to come along.” (PPT03)

Although PPT05’s interview was brief, they did specifically share their enjoyment of the bowling activity.

“I like bowling.” (PPT05)

Table 7

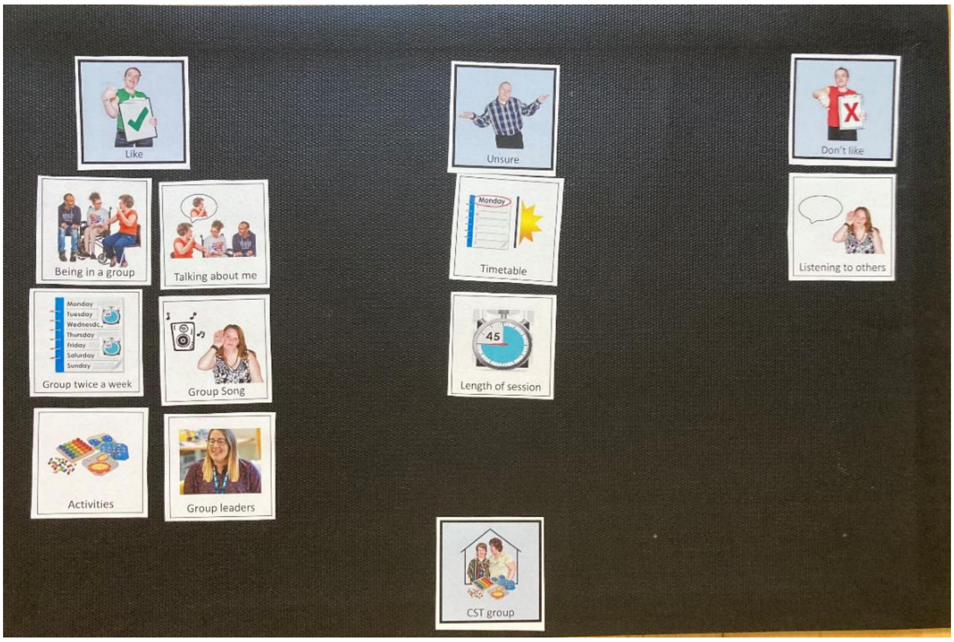
Content analysis summary of interviews for people with ID&D

Content Analysis Categories	**PPT01**	**PPT02**	**PPT03**	**PPT04**	**PPT05**
Pre-interview session/activity		Money: Like Bingo: Like	Money: Like	Word games: Like	Bowling: Like
All sessions	Like	Like	Like		
Being in a group	Like	Like	Like	Like	
Facilitator support	Like	Like	Like	Like	
Carer support		Like	Like	Like	Like
Session length	Unsure	Like	Like	Don't like	Like
Timetable	Unsure				
Number of sessions per week	Like (1 per week)	Like (1 per week)	Don't Like (1 per week)	Like (1 per week)	
Breaks in the middle of the session		Like	Like	Like	Like
Group Song	Like	Like	Like	Like	Like
Talking about experiences and ideas	Like	Like	Like		
Hearing others' experiences and ideas	Like (placed card under Don't Like)	Like	Like		
Comments/ suggestions			New people to join the group Would like to come more often		
Key interview considerations to note	Confused the 'timetable' card for the weather and the days of the week. Different comments about 'hearing other's experiences'. Unclear if ppt liked or did not like this aspect.	Verbally responded that they liked 'hearing about others' experiences', but then shared that some interactions with another participant have been 'annoying'.	Facilitator knocked on the door at the end of the interview and informed person with ID&D to rejoin the group (rushed ending).	Confused the 'unsure' Talking Mat symbol for 'smiling' Support from carer to help the person with ID&D stay focused on the interview questions. Hearing impairment. Only responded with 'like' when asked any questions.	Whispered responses (unintelligible at times). Carer shared that the person with ID&D had a recent difficult experience unrelated to the group, which created further deterioration in communication skills. The interview was terminated early (individual started to breathe heavily and whisper to self).

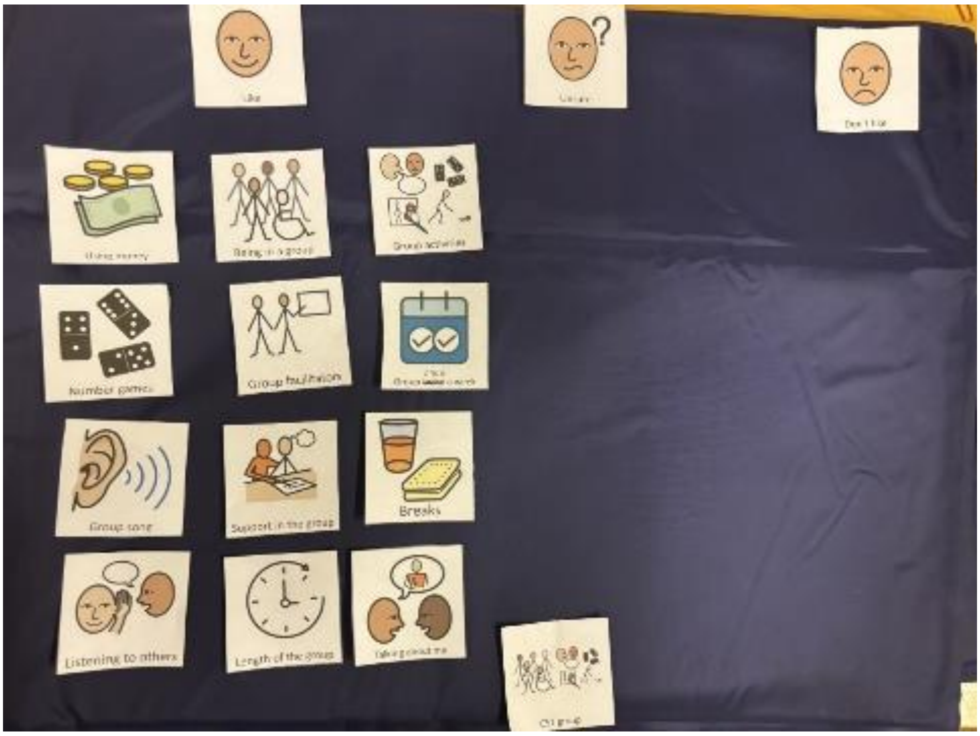
Figure 2

Talking Mats for people with ID&D.

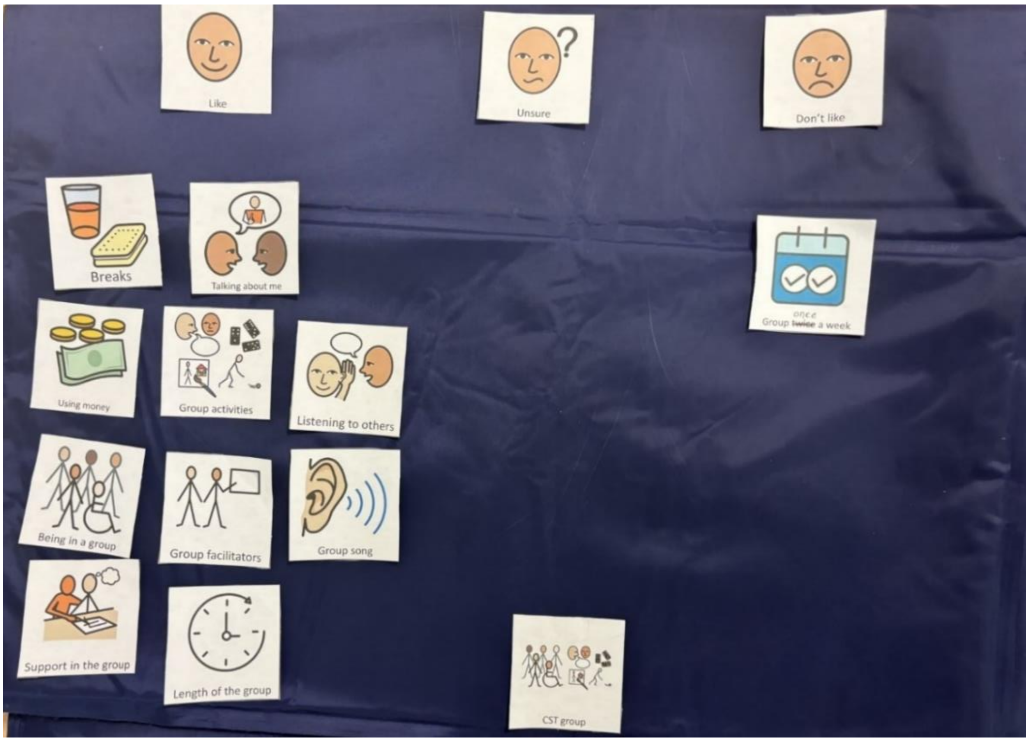
PPT 01



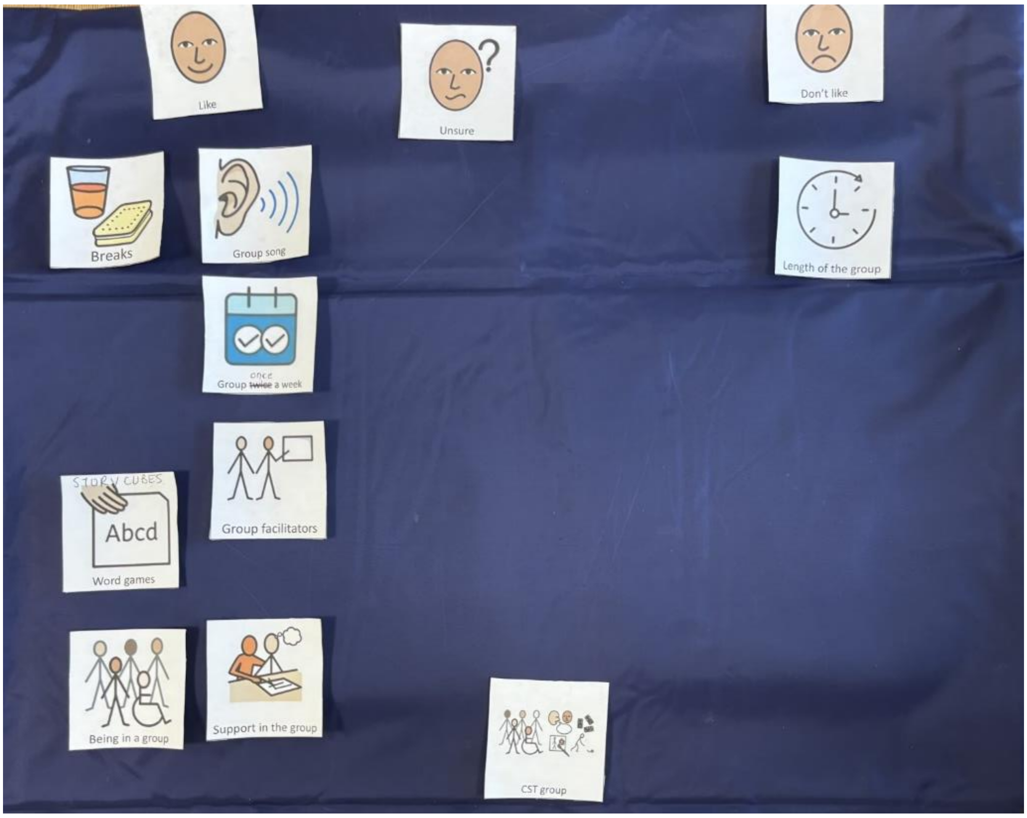
PPT 02



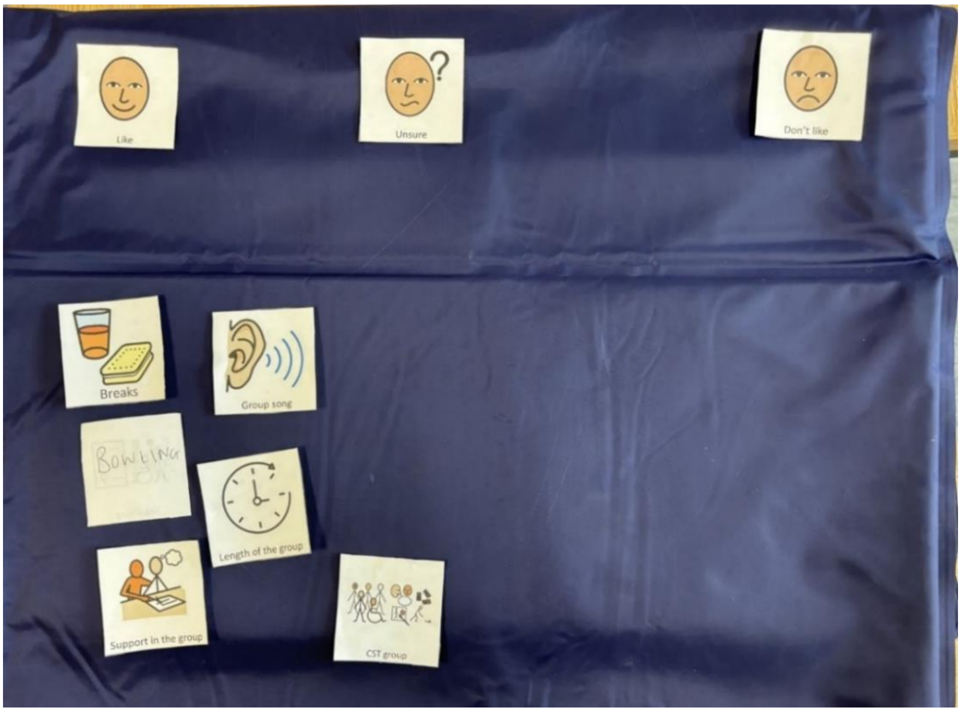
PPT 03


Like
Unsure
Don't like
Breaks
Talking about me
once
Group ~~twice~~ a week
Using money
Group activities
Listening to others
Being in a group
Group facilitators
Group song
Support in the group
Length of the group
CST group

PPT 04


Like
Unsure
Don't like
Breaks
Group song
Length of the group
once
Group ~~twice~~ a week
STORY CUBES
Abcd
Word games
Group facilitators
Being in a group
Support in the group
CST group

PPT 05



Discussion

Summary of findings

Factors which appeared to influence acceptability of CST-IDD (i.e. influenced how the intervention is received by group participants, facilitators and carers) were mainly attendance and perceived consequences of CST-IDD. Attendance was a good indicator of acceptability and was generally poor across most groups aside from one. A variety of positive and negative perceived consequences were reported as indicators of acceptability. Some of the perceived negative consequences were caused by various barriers, suggesting that the factors which influenced feasibility were likely to impact acceptability. For example, poor attendance was used as an indicator of poor acceptability, however, various barriers to participation (e.g. travel time) may have influenced the likelihood of attendance, and thus influenced the acceptability of CST-IDD. Positive outcomes were mainly described as shared enjoyment during the group.

Some group participants did experience some positive consequences outside of the group session for memory, communication, sleep and slower deterioration, but these were not reported for the majority of participants who attended the group. Therefore, from the perspective of facilitators and carers, the intervention did not appear to be acceptable for all group participants (e.g. poor attendance and varied perceived outcomes).

The feedback from people with ID&D highlights a generally positive perception of the group in terms of acceptability. Despite the various negative perceived consequences indicated by facilitators and carers, it seems that the effort from facilitators and carers did promote a positive overall experience of the group for the people with ID&D who were interviewed.

Feasibility of CST-IDD was discussed in terms of enablers and barriers to participation (group participants), facilitation (facilitators) and care provision (carers). A larger proportion of barriers (and enablers) were related to practical considerations, followed by the method of group delivery and then the actual CST-IDD content. These findings suggest even the most appropriate CST-IDD content may not compensate for practicality and set up limitations. These additional considerations may be specific to people with dementia and ID, creating a unique set of practical considerations that cannot be foreseen, requiring tailored planning and preparation. The CST-IDD content required adaptations, including those listed within the CST-IDD supplement and additional adaptations, in order to improve perceived outcomes (i.e. acceptability). With increased adaptations and considerations, feasibility reduces. However, some participants did not need any further adaptations to engage with the material or the CST-IDD supplement suggestions were sufficient, highlighting the heterogeneity within this population. Therefore, feasibility varied based on the presence of barriers and enablers, but individual differences were key in the determining the impact of certain barriers or enablers.

Adherence issues

There were some instances where the manual and supplement were not adhered to. Within the current trial, these influenced the feasibility of CST-IDD but are wider issues of adherence rather than feasibility. These included running two sessions in one day, despite the CST manual recommendation of two sessions a week on two different days. Due to other constraints with travel, carer and facilitator availability, this was the preferred option by all groups despite the potential issues for participant fatigue. A more convenient site location and additional carer resource would likely allow for the groups to be run on two different days and may be a useful consideration to add within the CST-IDD supplement (e.g. improving location convenience or considering participant fatigue if two sessions are run in the same day). Other issues included the use of a homework task in one group to collect newspapers for the current affairs session, leading to potential negative consequences of reading upsetting news material (which carers helpfully assessed as an unsuitable task for this participant). It may be another helpful note to include within the supplement to emphasise that there are no homework tasks. One participant did not have a hearing aid provided, which was a significant barrier to participation. However, this person would have been excluded as per the inclusion/exclusion criteria for CST-IDD. Therefore, it may be helpful to consider the criteria for participation within the supplement to re-assess suitability for the group in the first session. Another instance of non-adherence was the use of ‘correct answers’ to reinforce a sense of mastery, as this is avoided in CST to prevent disappointment from incorrect answers. This technique appeared to be useful in improving engagement for the specific group. Therefore, CST-IDD may benefit from including training or additional supplement considerations as to the use of ‘correct answers’ to promote a sense of mastery rather than disappointment.

The CST manual emphasises the importance of delivering groups for individuals with similar abilities, enabling tasks to be pitched at a suitable cognitive level. However, in light of recruitment difficulties and the wider heterogeneity of a dementia and ID population; this may not be possible and is likely to be a challenge in future implementation. This lack of adherence to this CST recommendation may have led to difficulties in personalising sessions. Despite the impact of potential mixed ability groups, the CST manual and CST-IDD supplement were developed with adaptation to the needs and abilities of participants in mind. This suggests a further training need for facilitators, or a need for additional facilitators to support with implementing some adaptations. One facilitator did note that it was difficult to know how much the session could be adapted, therefore further guidelines alongside the manual and training may provide clearer support in how to adapt CST-IDD for heterogenous groups. Additionally, smaller groups of participants with similar abilities may prove to be a more feasible option than larger groups with varied abilities.

All groups opted for carers to stay in the session where possible, and carers were generally noted to promote participation. However, some adherence issues were noted, such as carers responding on behalf of the participant. The manual noted that carers should not facilitate groups but did not make a clear reference to carer participation in the groups. Moreover, carers were not provided with any training or briefing, which may be a useful development to mitigate such issues.

Strengths and limitations

A key strength of the current study is the inclusion of the voices of people with dementia and ID, often lost within research processes (Muralidhar et al., 2024), facilitated with the use of a Talking Mat visual prompt. The key considerations for the interviews with people with ID&D (see Table 7) highlights some of the barriers which may usually result in not including a particular interview within an analysis. This study has highlighted that people with ID and dementia have important views to share and some of these barriers to the limited sample size and quality of interviews could have been mitigated with a careful consideration of various factors. For example, one person with ID&D appeared quite anxious, and the interview was terminated early. It could be speculated that if given time to get to know the interviewer and develop rapport (unlikely in a short 30-minute slot), this person with ID&D may have felt less anxious and more able to share their views for the duration of the interview. Other participants who were not interviewed had other scheduled activities or were feeling too tired after a long session. Interviewing group participants on the same day was proposed in order to prevent forgetting but may have failed to consider these limitations. This suggests that with some careful pre-planning (rather than introduced in the final two sessions), some of these interviews could have been facilitated around some plans or following a short recuperative break.

Likewise, a large proportion of the other qualitative interviews (nine out of 20) were facilitator perspectives. We could speculate that carer availability was limited, as this was shared as a barrier in some interviews. Facilitator interviews were generally longer than the others, suggesting that they may have been keen to share their experiences of running the group and therefore, were more likely to agree to participate.

Overall sample size limitations did impact the analysis and ability to draw a wider conclusion from interviews. Therefore, some of the key findings are based on individual responses or one to two interviews. In some instances, there are conflicting responses, for example, with interviews for people with ID&D, suggesting that although it captures the nuance of specific experiences, there is little sense of an ‘overall’ finding or opinion on CST-IDD.

Limitations relating to the wider CST-IDD trial design, such as the lack of demographic data for qualitative interviewees, alongside the implications of these outcomes will be discussed in part three of the thesis.

Recommendations and implications

Recommendations for future groups were made by facilitators and carers. Recommendations with some agreement across interviews are included in a summary table (Table 8). For example, one facilitator preferred a larger group of five to six participants, whereas others shared that the optimum size would be around three to allow for one-to-one attention. Therefore, there may be no ‘one size fits all’ for this population, and the recommendations listed below will provide a useful starting point for clinicians when considering CST-IDD.

CST content recommendations suggest that there was an overall issue with some resources and content which may need to be reviewed for people with dementia and ID (e.g. larger pictures and games). In clinical practice it may be more feasible to adapt to individual participant needs, especially within a learning disability team where there is often increased familiarity between staff members who are likely to run such groups and potential participants. Staff teams may be better able to recruit individuals who have similar abilities or adapt groups to a greater extent, compared to a research study where there is little familiarity at the planning stage.

Table 8

Summary of recommendations for future groups from facilitator and carer interviews

	Group delivery and set up
Personalisation	Personalised to participant interests
Set up	Meeting participants and carers before the first session to gather key information (e.g. personal interests)
	Meet participants in between sessions to improve confidence and familiarity
	Pre-adapted resources
	Planning the break in more detail
	Plan to continue activities at home if beneficial
	Single borough groups only (minimises unmanaged risk)
	Plan sessions in detail (e.g. check access to resources)
	Thorough risk assessment and planning
	Specific inclusion criteria (mild ID and dementia) or a similar level of functioning per group
	Practical considerations
Carer Support	Remain nearby to support
Distance/travel	Convenient location for all
	Transport options
External environment	Mid-morning session
	No extreme temperatures
Session/day structure	Shorter sessions (not two hours)
Site/venue	Check room suitability
	CST content
Activities/sessions	Active games rather than sit down activities
	Creative activities
	No fine motor activities
	Larger games (increased accessibility)
	Appropriate activities for available provision (check food safety, kitchen requirements)
	Less based on intact communication and more sensory driven (arts, painting)

A more general implication highlights the importance of enabling the participation of people with dementia and ID in both interventions and within research processes. Inclusion requires a whole person approach to understand the needs, likes, dislikes, strengths and difficulties unique to each individual (e.g. personhood; Kitwood, 1997). In line with the emphasis on providing person-centred care when considering the needs of people with ID (Department of Health and Social Care 2001; 2010) and people with dementia (Kitwood, 1997), interviews and group CST with group participants often required a flexible, tailored approach. Within the current study, including the perspective of group participants regardless of the 'standardisation' of interview processes was imperative in capturing group participants' subjective experiences of the group, arguably the most important perspective. Considering personhood included taking into account individual strengths (e.g. one participant's enthusiasm for including their friend), alongside some of the individual difficulties in engaging in a formal verbally based interview process (e.g. recording gesture responses such as nodding or shaking head) rather than excluding their perspectives from the research altogether. Including the voice of the individual required further consideration at the analysis stage, where a content analysis rather than thematic analysis was used. Due to limited detail, a thematic analysis may likely have rendered these unsuitable for further analysis. However, a flexible approach to the analysis by including the Talking Mat images alongside the additional context of some of the participant interviews allowed for all participant interviews to be included with additional considerations. Therefore, the inclusion of the voice of people with dementia and/or ID should be flexibly led by their needs in order to facilitate choice and autonomy in how their care is set up (e.g. 'Valuing People' and 'Valuing People Now'; Department of Health and Social Care, 2001, 2010).

Conclusion

This study is the first to investigate the qualitative experiences of group CST-IDD with individuals who have dementia and ID, group facilitators and carers.

Despite separation of acceptability and feasibility by the initial research question, it appeared that the acceptability of CST-IDD, was heavily influenced by the presence or lack of factors which improved or hindered the feasibility of CST-IDD. For example, having a perceived negative consequence from attending the group, may indicate poor acceptability. However, when this negative consequence is influenced by the consideration of various practical barriers, mitigating these barriers to improve acceptability would decrease feasibility of running this group.

CST-IDD was acceptable for some participants, facilitators and carers. However, for others, their experiences of the group were heavily influenced by various barriers and enablers, including their individual circumstances and needs. A consideration of these barriers and enablers indicated that the feasibility of CST-IDD was dependent on multiple individual and group level factors, both planned and unplanned. For example, additional considerations may be required in order to improve perceived positive outcomes (i.e. acceptability) for some individuals, such as skilled facilitators and additional adaptations, thus reducing the feasibility of running this intervention if various conditions are required in order to improve acceptability.

It is important to note that the limited feasibility of group CST and the level of adaptation required, highlights a significant service need to provide creative supports for people with dementia and ID. The outcome of these findings should not be used to reduce the available supports but understand that we are currently not set up to provide an acceptable and feasible service in line with valuing Personhood (Kitwood & Brooker, 2019) and Citizenship (Swinton, 2021) for this population. The current small-scale acceptability and feasibility study (within a wider trial) lends itself to a tentative conclusion that this population is highly heterogenous, and CST-IDD in its current form, is likely to be an acceptable and feasible intervention for some, rather than all individuals with dementia and ID.

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PART 3: CRITICAL APPRAISAL

Introduction

This critical appraisal discusses part two in further detail. The first part the critical appraisal will expand on further discussion relating to the general CST-IDD trial (rather than the qualitative research process, addressed in part two). The second part will expand on the reflexivity statement in relation to the qualitative analysis. The final section will reflect on the process of working within a larger NIHR funded trial.

Further discussion

Part two of the thesis discusses the qualitative interview process. However, there were additional discussions, limitations and implications in relation to the wider research process. These may be important when considering the acceptability and feasibility of running a research trial for individuals with ID and dementia.

Using an RCT design with this population

The RCT design of the CST-IDD trial, allocated some participants to the CST-IDD intervention and others to treatment as usual (TAU). The importance of offering a RCT for people with ID and dementia is in line with the need for high quality interventions as recommended by national guidance (Public Health England, 2018). However, some facilitators expressed frustration that they had spent a lot of effort to identify suitable participants who would benefit from the group, but these individuals ended up in the TAU condition. In addition, some of the groups did not have consistent attendees, suggesting that some of the other individuals who ended up in TAU may have been offered these sessions if they were on a clinical waiting list for the intervention (rather than a research trial). Within clinical practice, a more flexible methodology may have been adopted to deal with recruitment and retention difficulties, for example, inviting individuals from a waiting list to replace those who had dropped out or refused to attend after session one. Within research, the RCT design provides a realistic reflection of effectiveness by allowing further analysis with those who remain and those who dropped out and thus it would not be possible to offer the same intervention to those in the TAU condition. Providing a wait list control group for those in the TAU condition may have provided the opportunity for individuals in the TAU condition to benefit from the intervention.

Experiences of the CST intervention or the research process

Facilitators expressed general positives and negatives about the CST-IDD intervention, such as wasted clinical time in preparing resources or having all the recruitment and resources ready to go by the research team. However, it was unclear as to whether these experiences directly related to aspects of the CST-IDD intervention or due to the general research processes such as having to travel to a particular site that was approved for the purpose of the study or factors such as slow recruitment. It may be useful to provide an introduction to a research trial for facilitators and carers in terms of aiding their understanding of the nature of a clinical trial. For example, setting some expectations of a research process. When facilitators and carers shared their views about the intervention in some of these interviews, it was difficult to disentangle what was caused by the research processes and what was caused by the actual CST-IDD intervention. Therefore, a larger scale trial may benefit from a clearer separation between feedback on the research processes and feedback on the CST-IDD intervention.

Cohort effects

It was observed that many of the individuals with ID and dementia who attended the CST-IDD groups often had other activities which clashed with qualitative interview timings. In addition, others were having to take time out of college or activity groups to be able to attend the specified dates for the CST-IDD group. Therefore, it could be suggested that as a cohort of individuals, people with ID and dementia might be engaged in more activities compared to when CST was initially developed for people with dementia in 2003. At the time, CST was developed with the understanding that a poor social environment would contribute to further decline for people with dementia (Spector et al., 2003). This may indicate a much-needed cohort shift in the provisions that are available and recommended for people with dementia and ID. There is a further question as to whether an individual’s daily schedule should be considered alongside the recruitment process to determine whether CST-IDD will have an impact over and beyond the individual’s current repertoire of activities (if scheduling is an issue). This hypothesis may explain some of the limited improvements in longer-term outcomes, where if individuals are provided with ample stimulation and a positive social environment, they may have reached the ‘ceiling’ effect of a slower decline, leaving little room for CST to improve their social environment. Although it is important to include the views of people with ID and dementia within the research, their attendance at routine activities for their wellbeing should not be hindered by their involvement in research processes. In addition, to avoid reliance on long-term memory of the group sessions, these interviews were solely facilitated in the final two sessions, decreasing the flexibility in scheduling group attendee interviews. It may be useful to consider the importance of gathering feedback from individuals with dementia and ID in advance, planning around their scheduled activities, where this would be facilitated for other individuals (e.g. facilitators and carers). Despite the person with dementia and ID's reliance on carer schedules, their contributions to research should be valued in the same way and accommodations made for in relation to such scheduling issues (e.g. additional research team members allocated to complete interviews with group attendees, collecting information regarding availability in advance and providing additional reminders to carers) For example, in the current intervention, this may have involved some continued liaison with carers to ensure that participants would be free for an interview session, rather than checking availability a week in advance or on the day.

Another cohort effect noted was potential societal changes that may not reflect the resources used within CST-IDD. For example, money has changed in recent years, and one facilitator noted the change to money as barrier in the 'using money' session. Some individuals may not use any money (e.g. limited in activities of daily living), others may not be as familiar with newer money or alternatively, some participants may be better versed in newer payments methods (e.g. contactless card payments). Similarly, the food session used some play food, with labelling that might not be easily recognisable, and some facilitators did comment on the play food as being 'too abstract'. For example, participants may struggle to recognise an obscurely labelled play can of baked beans. However, if given the label of a well-known baked beans brand in the UK, such as a can of Heinz, this task is more accessible and allows for better engagement. Therefore, group resources and activities may need to be reviewed as a 'one for all' approach may be disorientating or outdated for some.

Key incidents and learning

There were also some key incidents of note in terms of how risk and harm were managed within the RCT. One participant 'pretended' to feel unwell in order to leave the group and another participant was highly anxious. In both these instances, both participants possibly should have been supported to leave before these escalations to prevent harm. Carers in these instances did respond (e.g. providing the participant with their own space away from the rest of the group), and both did not return following the first session. For a group where verbal communication may be limited, it is important to consider how participants might communicate their distress or want to leave the group in a safe way that respects their choice to stay or leave, especially when there has not been a similar group trial in the past. These methods that were used did not seem safe or in keeping with respecting the choices of participants, as it took extreme expressions of distress for these to be acted upon. In addition, the cross-borough group shared limited access to some participant notes. This led to some issues when risk was identified for one attendee, and facilitators proactively liaised with the relevant staff members. Detailed risk assessments for participants should have accounted for the fact that there were no facilitator representatives from particular boroughs, and a decision should have been made to either include a representative or not offer the group to out of area participants. This is a key learning point about the safety of facilitating larger groups, where facilitators do not have access to important information, and important considerations to note where an intervention is being trialled for the first time within a population (leading to unknown risks).

Exploration of reflexivity

In qualitative research, there is an emphasis on understanding the subjective compared to quantitative research, which seeks to remain objective and ‘separate’ from the data (Young and Ryan, 2020). Reflexivity is a process in which researchers, mainly qualitative, engage in to understand how their subjectivity within the research is shaped by their experiences and context. There is a complex interaction between researchers and participant characteristics, from the stage of research design to implementation to analysis and write up (Olmos-Vega et al., 2023). There are many ways to approach reflexivity (Gentles et al., 2014) and it could even be suggested that the current method of reflexivity will be influenced by my current context and identities. The approach I take is one that acknowledges the influence that my context may have had on the current research processes, rather than one that emphasises a need to remain ‘neutral’ or ‘bracket’ these identities to minimise their impact on the research process (Neubauer et al., 2019). Taking this a step further than simply acknowledging the impact on the research process, rather than taking a lens of criticism (Malterud, 2001), an open dialogue will be used to facilitate further thought more in line with qualitative research that values researcher subjectivity as a core part of the co-constructed meaning between participant and researcher (Charmaz, 2006; Koopman et al., 2020). Walsh (2003) describes four key areas of reflexivity as interacting, including: interpersonal, personal, methodological and contextual. These areas will be briefly discussed in turn in relation to carrying out, analysing and writing up the findings from the qualitative interviews.

Interpersonal

When interviewing facilitators, there may have been a shared understanding as ‘colleagues’ working within a shared NHS system. As a trainee psychologist, interviewing facilitators within whom I shared a similar role (e.g. clinical psychologists) may have created further alignment in terms of professional values and interview style compared to those who had a different role (e.g. carers, psychiatrists, occupational therapists). I noticed that this was the case for both myself and how I related to facilitators’ experiences of the group and how much some facilitators felt comfortable to share within the interview. Thinking about the power dynamics of asking individuals to report their honest views about a trial that I am a part of, I also did notice some reluctance to share ‘negative’ comments about the trial. When this reluctance did show, I often found myself validating the struggles that had been mentioned (e.g. needing to set up group resources) in an attempt to create a safe space. However, despite my very best efforts, there would likely have been an element of my relationship to the CST-IDD trial which may have affected the type of information that was gathered during the qualitative interview process. When interviewing group attendees, there was shift in my interactions, where I did feel like I had stepped into a more caring role, in comparison to interviews with facilitators and carers. I felt that although I had a ‘researcher’ title and set up, my approach was also clinically led, which led to some difficulties in remaining impartial when the person with dementia and ID required some other form of support. For example, one individual appeared to become quite anxious during the interview process, and taking this person’s clinical presentation into account, it was important to stop the interview (as a researcher) but also check in with how the person was feeling and if there was anything they needed to feel comfortable in that moment (as a clinician). Terminating this interview early due to potential harm was in line with the research ethics but checking in with the individual to ask them about their plans later in the day to provide a less ‘abrupt’ ending was informed by my clinical experience and profession. In another instance, one individual could not engage with a verbal interview. The individual’s carer was mindful that the individual may have felt disappointed by their reluctance to participate in the interview and brought up some easier questions that they knew the individual could respond to. I chose to spend some time with this individual and their carer. It seemed that this interview ended up being a positive interaction for this person, as they seemed to enjoy sharing their knowledge. This interaction is a key example of how we did not achieve the aims of the research process, to complete an interview, but facilitating a positive interaction may have been more helpful than asking the individual to leave the room feeling disappointed in their performance. Moreover, creating a positive experience of the research process is crucial in supporting the individual to engage with other aspects of the research.

Personal

With the analysis of interviews, my perspective did influence the coding process at times, especially with the development of a posterior codes. I found myself falling into a ‘clinician’ perspective at one point during the analysis stage, where I started to solely use facilitator interviews to inform the codes. Reflecting on why I may have prioritised facilitator interviews may have been both due to my limited research experiences, in comparison to my clinical experience but also my alignment with facilitators as a clinician who has facilitated similar groups. Whilst noticing this process, I made a conscious effort to incorporate carer interviews within the coding framework, and soon found that there were additional codes that were important within carer interviews, but these were less prominent within facilitator interviews. However, this is one aspect of my identity that may have influenced the coding process, and I was able to sit back and reflect in order to remedy this bias to some degree. However, there would likely have been a myriad of other personal factors such as my age, ethnicity, upbringing, social class, education, ability and so on, that did impact my coding approach.

For example, most of the group participants (83.3%) were of English/Welsh/Scottish/Northern Irish/British ethnicity with one individual from a mixed background and another from an Asian background. One interviewer noted the session content being based in British culture and an assumption that participants are familiar with British tv shows and common games. However, as someone who is from the global majority I found myself considering those smaller groups of participants, facilitators and carers who maybe could not access some of the material due to a non-British upbringing or experience. It is also useful to note that there was little ethnic diversity across group participants (compared to carers for example) suggesting that there are further barriers to recruitment in such interventions for people with ID and dementia who are from the global majority. Additionally, even if people with ID and dementia did grow up in the UK, their experiences as a person with ID are likely to be different to those who would usually attend CST groups (individuals from the general population who develop dementia). For example, one assumption is that pop culture such as tv shows and music, or active games may not have been inclusive enough to involve people with ID during their early years to the same extent that these would have for people within the general population. In terms of adapting session material to be culturally sensitive, a training section dedicated to cultural adaptations was provided, but potentially the limited ethnic diversity of group participants alongside the time required to consider these adaptations led to little capacity for the implementation of culturally sensitive adaptations. Future groups may benefit from further exploration of the demographics of all individuals within the groups, including carers and facilitators, to inform group adaptations.

The influences of such considerations, based on my experience and aspects of identity do not provide a ‘straightforward’ appraisal of these influences. Some may be useful, considering factors that others without these identities may not attune to, however, as noted previously, these may also lead to additional sources of biased interpretations of the data.

Methodological

The decision to use a thematic analysis was informed by discussions with the qualitative lead for the main CST-IDD trial. An inductive and deductive coding approach was decided, based on the semi-structured interview style. In addition, there was some variety in what interviewees felt were important for the groups they were a part of and also shared their own personal experiences of the group. However, this approach meant that there was less room for synthesis, as individual differences were accounted for to a greater extent, compared to an approach that may have just categorised the data by the pre-existing code book. There are benefits to both approaches, where a more simplified code book could have a better summary conclusion and overall implication. However, my own ethos for research and clinical work is one that values the individual contributions as important considerations. This ethos is likely to have influenced my decision to also include a posterior codes, informed by the key codes within the data.

Contextual

In terms of the context around the interviews, group attendees were often aware that they were attending a group, but in terms of participation in a research project, many had a consultee consent on their behalf. Therefore, when individuals did attend the group, to ask them to stay after the group, did feel difficult to explain at times, and I was conscious about making the experience as enjoyable as possible. Using the talking mat methodology helped in this instance, as it made the interview feel more informal and ‘activity-like’. Thinking about the wider context of each group, there were differences in how the group was run across the different teams, which impacted the way in which qualitative interviews were scheduled. For example, some groups were run in a familiar building for facilitators, and organising a space for each interview was straightforward (or requesting a new space if this was not suitable). However, for some sites, facilitators were unfamiliar with the location, and as such, finding a suitable room (e.g. with mobility and access requirements) was difficult during these instances. In addition, my context as an external member of the research team, requesting access to various rooms to set up for the interviews felt like an unreasonable request at times, especially when facilitators were arriving early in order to set up for the group to run on time. During these instances, I found myself offering support to help with setting up for the group. Meeting some of the facilitators beforehand when conducting group attendee interviews meant that when the facilitator interviews were carried out over Microsoft Teams, there was an easier flow of conversation between those I had previously met compared to those I had not met, likely influencing the quality of the data gathered at interview. Whether this had a positive or negative impact, or just a difference, is difficult to ascertain. If familiarity with a facilitator meant that they felt more comfortable to share openly, this would have been a positive impact. However, if familiarity meant that they assumed that I would know about some details, without fully elaborating in an interview, this would have negatively impacted the data collection process.

Reflections on working within a pre-existing trial for CST-IDD

My role was one of two trainee clinical psychologists supporting a wider National Institute for Health and Care Research (NIHR) funded trial. My initial project was to support with the collection of some quantitative data, analysis and write up the quantitative details of the research study with the other trainee who was to focus on the qualitative details. As such, when I did join the trial, the process of recruitment was under way and ethical approval was in place. As part of this process, I was involved in collecting follow up assessments at the first site and planned to support with quantitative data collection across the various other sites. However, as the trial progressed, there were issues with slower-than-expected recruitment, thus leading todifficulties for the second trainee in completing their qualitative write up of the research. It was decided that there would be little need for additional quantitative support, but there was limited resource for the qualitative interviews as the other trainee was set to graduate before all groups were completed (due to the recruitment delays). Therefore, I continued with the qualitative project.

As such, the development of the interview schedules, research questions and some interviews (1 facilitator, 1 carer and 1 participant interview) were completed by the other trainee. As there was some overlap between us, I was able to consult with the other trainee in running through each of the interview schedules in detail (including the talking mat methodology for group attendee interviews).

However, not having been a part of the initial stages of the qualitative research process led to some additional steps during the analysis and write up stage.

Qualitative analyses often emphasise the importance of researcher familiarity with the data from carrying out interviews to transcription to coding and write up (Byrne, 2022). I noticed that it was particularly difficult to analyse the three interviews that I had not carried out or transcribed at the stage of analysis. I did spend a longer period of time on these interviews during the familiarisation stage. In hindsight, although this process did take longer, the initial lack of familiarity with these interviews almost enabled a more thorough familiarisation process. Whilst analysing the interviews I had conducted, reflecting back on the process, I did spend less time during the familiarisation process which may be due to having been familiar with the actual interview or an unhelpful assumption which could have hindered the analytic process. Both our interviews, despite individual differences in talking style, often had a validating stance embedded throughout, for example, when interviewees expressed frustrations, our approach was in line with our clinical training, to be validating and empathic. This led to some reflections on the type of interviewer, and how important interviewer experiences are in eliciting certain responses from the interviewee. It could be argued that an overly validating stance may draw out more negatives than positives, whereas a neutral less validating stance would possibly have created a more balanced opinion. It could also be suggested that creating a safe space for interviewees to be able to voice any frustrations with the research process was key in this particular piece of research, where acceptability and feasibility is being determined. In addition, as a clinician within similar services, I found it difficult to not align strongly with facilitators, as I myself have facilitated groups in the past and did share some of the experiences that were voiced in the interviews.

Reflecting on the experiences of being part of a wider research trial, within my other research experience I have been the main researcher with support from a supervisor. Being part of a wider team came with several benefits, such as having a wide array of expertise to seek guidance from, for example, being able to consult with the qualitative lead for the trial during the analysis stage. In addition, I was able to get involved with some of the data collection, and understand the complexities around data storage, NHS approvals and ethics, consent processes and so on, without having to manage the entirety of data collection for this particular trial. Furthermore, when issues did arise, we had a wealth of expertise and knowledge to be able to deal with the issue at hand. However, there were specific issues that did arise, possibly due to the parallel processes taking place at one time due to the impact of having a large team involved in this trial. For example, the demographics for the main trial were collected when group participants completed their baseline and follow up assessments, along with carer demographics. However, in terms of the qualitative trial, there was little information regarding a demographics form, and many individuals were involved in collecting consent forms at this stage. Some sites required retrospective consent collection, which was a process I supported with as part of my involvement in the trial. Similarly, initial information regarding demographic collection highlighted that there was no ethical approval to collect separate demographics during the qualitative part of the trial. However, when all monitoring actions were completed, a facilitator demographics form was found amongst other documents and should have been collected for facilitators in this instance. This experience was a key learning point for all involved within this trial, and I also gained an understanding of the appropriate actions required in order to rectify such an error (e.g. further escalation and completing a protocol violation form.). In addition, being part of a trial that was run by a different NHS trust to my current placements was a further challenge in being able to access trial related data, including ethical approval details. These experiences have broadened my understanding of the complexities involved in trialling an intervention (albeit a small-scale feasibility study) and the necessary supports needed in order to facilitate a successful trial.

At the time, although frustrating as a situation to have to move from a quantitative to a qualitative project, there was an opportunity to work in line with an ethos that I valued more that I had realised. As a clinical psychologist we have the privilege of being able to be a part of the research process and the clinical team who are at times involved in delivering such interventions. Being able to support the individual with dementia and ID to express their opinions about the CST-IDD group and facilitating these discussions was a highly rewarding experience for me and an incredible learning experience.

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APPENDICES

Appendix A: Further specific details for included studies

Study	Total ppt N	ID and dementia diagnosis details	Gender, age range and comorbidity details	Intervention and details
Dodd et al., (2015)	*n*= 72	Approx. *n*= 64 (out of 72) had early/mid/late stage dementia and ID diagnosis Included 2 phases 1) Face Validity Trial: 21 (19 Down's syndrome, 2 non specified ID). All diagnosed with dementia. 2) Main Pilot Phase: all 56 had dementia and only 89% had a diagnosed ID.	Gender and comorbid symptoms not included Ages 46 to 65	N/A
Ali et al., (2022)	*n* = 40	Mild/moderate ID and mild/moderate dementia. Down's Syndrome (*n* = 23); Alzheimer's Disease (*n* = 27); Mild dementia (*n* = 22).	Age range not included. Comorbidity: hearing problems (*n* = 9); visual problems (*n* = 6); Epilepsy (*n* = 8)	40 sessions of iCST

			Control group: female (*n* = 15) and male (*n* = 5) Intervention group: female (*n* = 8) and male (*n* = 12).	
Ryan & Dodd (2023)	*n* = 49	Down's Syndrome and highly suspected or confirmed dementia	Comorbid symptoms and age range not included. Female (*n* = 28) and male (*n* = 21)	N/A
Watchman et al., (2021)	*n* = 16	Down's Syndrome (*n* = 13); Other intellectual disability ((*n* = 3) Alzheimer's Disease (*n* = 4); vascular dementia (*n* = 2); dementia & type not specified (*n* = 10)	Comorbid symptoms not included. Female (*n* = 10) and male (*n* = 6) Ages 38 to 77.	2 to 6 interventions each **Cycle 1** (*n* = 7) **-** reminiscence, music playlist, aromatherapy, cooking, time tracker, exercise, design changes-flooring, design changes - lighting to living room and bedroom, design changes- lighting to bedroom, design changes - curtains, design changes-night lights, cognitive games **Cycle 2** (*n* = 9) **-** Music playlist, reminiscence, exercise, tea dance, namaste care, board games/jigsaw, design changes - lighting to bedroom. design changes - adaption to stairs,

				adapted cutlery, arts and crafts, cooking, twiddlemuff, animal therapy, robotic cat, dementia singing group, activity planning
Moss & Patel (1995)	*n* = 105 with ID	*n* = 12 (out of 105) with definite diagnosis of dementia; Down's Syndrome (*n* = 5); other ID (*n* = 7)	Age range and comorbid symptoms not included. Female (*n* = 44) and male (*n* = 61); not included gender for *n* = 12 population with dementia & ID	N/A
Cooper (1997)	In total: *n* = 134 with ID	*n* = 29 (out of 134) with diagnosis of dementia	Comorbid symptoms recorded but included in paper Female (*n* = 19) and male (*n* = 10) Ages 69 to 94	N/A
Finnamore & Lord (2007)	*n* = 8; all diagnosed with ID	Alzheimer's Disease (*n* = 5); Lewy Bodies Disease (*n* = 1); Dementia but unclear diagnosis (*n* = 2)	Gender, age range and comorbid symptoms not included	Dementia Care Mapping: observations by 2 mappers at a time for 2 hrs, 24 hrs in total Shorter map than usual of 2 hrs (rather than 6) to support care planning and problem solving Over an 18 month period, completed 12 maps

				Aim to evaluate QoL and improve based on findings
Thompson (2003)	*n* = 16; all diagnosed with dementia	Down’s Syndrome (*n* = 8); other ID (*n* = 8)	Comorbid symptoms not included Female (*n* = 9) and male (*n* = 7) Ages 35 to 66	N/A
Forrester-Jones et al., (2017)	In total: (*n* = 9) all with ID	*n* = 6 (out of 9) diagnosis of dementia	All ppts: multiple medical diagnoses (not specified; physical disabilities (*n* = 8); mental health difficulties (*n* = 1); Female (*n* = 7) and male (*n* = 2) Ages 24 to 68 (includes ppts with and without dementia & ID)	N/A
DeVreese et al., (2012)	In total: (*n* = 40) all with ID	*n* = 20 (out of 40) diagnosis of dementia; Down’s Syndrome (*n* = 17); other ID (*n* = 3)	No current comorbidities Female (*n* = 22) and male (*n* = 18) Ages 45 to 68 Includes all participants not just dementia & ID population	N/A

Dodd (2010)	In total: (*n* = 31) all with ID); Down's Syndrome (*n* = 30); other ID (*n* = 1)	*n* = 13 (out of 31) diagnosis of dementia; suspected dementia (*n* = 8); no dementia (*n* = 10)	Comorbid symptoms and gender not included Ages 43 to 68	N/A
Ghazirad et al., (2022)	Total (*n* = 2): 2 case studies only 1 suitable for inclusion	(*n* = 1) diagnosed Alzheimer's disease and ID.	Gender not included Comorbidity: anaemia and epilepsy 71 years old	N/A

Appendix B: Full COSMIN checklist appraisal process

(1) PROM Development	(2) Content Validity	(3) Structural Validity	(4) Internal Consistency	(5) Cross-cultural Validity/Measurement Invariance	(6) Reliability	(7) Measurement Error	(8) Criterion Validity	(9) Hypothesis testing for construct validity	(10) Responsiveness
Dodd et al. (2015) – QOMID									
1 – V. good 2 – V. good 3 – V. good 4 – V. good 5 – V. good 6 – V. good 7 – N/A 8 – V. good 9 – N/A 10 – Adequate 11 – N/A 12 – N/A 13 - N/A 14 – V. good 15- V. good 16 – V. good 17 – V. good 18 – Adequate 19 – V. good 20 - N/A 21 – N/A 22 – N/A 23 – V. good 24 – Adequate 25 – V. good 26 – Doubtful	1 – Doubtful 2 – Doubtful 3 – N/A 4 – N/A 5 – N/A 6 – Doubtful 7 – Doubtful 8 – Doubtful 9 – Doubtful 10 – N/A 11 – N/A 12 – N/A 13 – Doubtful 14 – Doubtful 15 – Doubtful 16 – Doubtful 17 – N/A 18 – N/A 19 – N/A 20 – Doubtful 21 – Doubtful 22 – Adequate 23 – Adequate 24 – Doubtful 25 – Adequate 26 – Doubtful	1 – Adequate 2 – N/A 3 – Inadequate 4 – V. good	1 – V. good 2 – V. good 3 – N/A 4 – N/A 5 – V. good	N/A	N/A	N/A	N/A	N/A	10 (a) & 10 (b) – N/A 10 (c) 8 – V. good 9 – V. good 10 – V. good 10 (d) – N/A

	27 – Adequate 28 – Adequate 29 – Doubtful 30 – Doubtful 31 – Doubtful								
Ali et al. (2022) QOL-AD & HADS (identical quality assessment for both)									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	10 (a) & 10 (b) & 10 (c) - N/A 10 (d) 11 – V. good 12 – V. good 13 – V. good
Ryan & Dodd (2023): QOMID									
N/A	N/A	N/A	N/A	N/A	– N/A	N/A	N/A	N/A	10(a) – N/A 10 (b) – N/A 10 (c) 8 – v. good 9 – v. good 10 – v. good 10 (d) – N/A
Watchman et al. (2021) QUALID									
N/A	N/A	N/A	N/A	N/A	1 – Doubtful 2 – V. good 3 – Adequate 4 – N/A 5 – Inadequate 6 – N/A 7 – N/A 8 – V. good	N/A	N/A	N/A	10 (a) – N/A 10 (b) 1 – V. good 2 – doubtful 3 – V. good 4 – v. good 10 (c) – N/A 10 (d) 11 – V. good 12 – V. good 13 – V. good

Watchman et al. (2021) Goal Attainment Scale									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	10 (a) & 10 (b) & 10 (c) - N/A 10 (d) 11 – V. good 12 – V. good 13 – V. good
Watchman et al. (2021) NP1-Q									
N/A	N/A	N/A	N/A	N/A	1 – Doubtful 2 – V. good 3 – Adequate 4 – N/A 5 – Inadequate 6 – N/A 7 – N/A 8 – V. good	N/A	N/A	N/A	10 (a) – N/A 10 (b) 1 – V. good 2 – doubtful 3 – V. good 4 – V. good 10 (c) – N/A 10 (d) 11 – V. good 12 – V. good 13 – V. good
Moss & Patel (1995) PAS-ADD									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	1 – N/A 2 – V. good 3 – V. good	9 (a) – N/A 9 (b) 5 – V. good 6 – V. good 7 – V. good	N/A
Cooper (1997) PPS-LD									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Finnamore & Lord (2007) DCM									
N/A	2 (a), 2 (b), 2 (c) – N/A 2(d) 22 – Doubtful 23 – Doubtful 24 – Doubtful 25 – Doubtful	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

	26 – Doubtful 2 (e) – N/A								
Thompson (2003) HADS									
N/A	N/A	N/A	N/A	N/A	1 – V. good 2 – V. good 3 – Adequate 4 – N/A 5 – inadequate 6 – N/A 7 – N/A 8 – V. good	N/A	N/A	N/A	10 (a) & 10 (b) - N/A 10 (c) 8 – v. good 9 – v. good 10 - V. good 10 (d) – N/A
Forrester-Jones et al., (2017) DEMQOL – Proxy									
N/A	N/A	N/A	1 – V. good 2 – V. good 3 – N/A 4 - N/A 5 – V. good	N/A	N/A	N/A	N/A	N/A	N/A
DeVreese et al. (2012) – QUALID									
N/A	N/A	1 - inadequate 2 – N/A 3 – Inadequate 4 – v. good	1 – V. good 2 - N/A 3- V. good 4 - N/A 5 – V. good	N/A	1 – Adequate 2 – v. good 3 – Adequate 4 – V. good 5 – N/A 6 - N/A 7 - N/A 8 – v. good	N/A	N/A	9 (a) 1 – V. good 2– V. good 3 – V. good 9 (b) - N/A	10 (a) & 10 (b) – N/A 10 (c) 8 – V. good 9 – V. good 10 – V. good 10 (d) - N/A
Dodd (2010) DEMQOL and DEMQOL – Proxy									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Ghazirad et al. (2022) NPI-Q									
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Appendix C: List of resources provided with the main CST manual and CST-IDD supplement

- Bean bags
- Skittles
- Large dice and ‘my life’ board game
- Play food cans
- Food/toy boxes
- Felt tip pens
- Card making kit
- Toy farm animal set
- Small vehicles
- Pretend money
- Large card for number games
- Large dominoes
- Large snakes and ladders
- Bingo kit

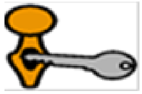
Appendix D to Appendix K: Information Sheets, Consent Forms and Interview Schedules

Information sheets, consent forms and interview schedules have been completely anonymised with all contact details, photographs of researchers, names and trust logos removed to preserve individual and site confidentiality.

Appendix D: Information Sheet for people with ID&D (group participants)

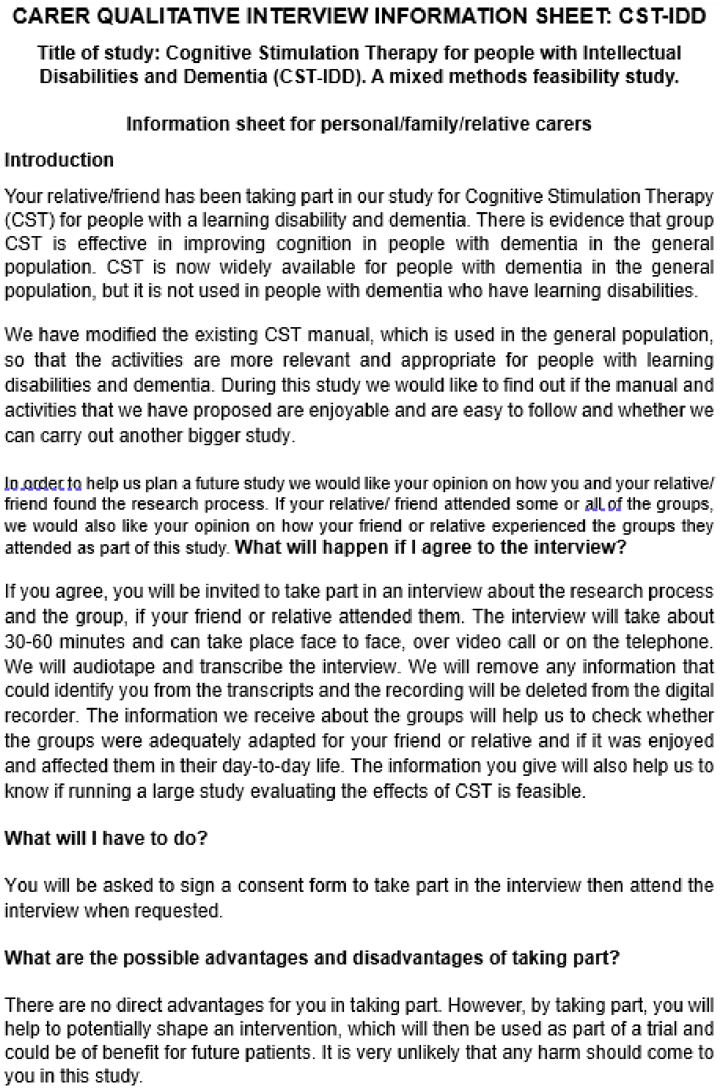
PARTICIPANT INTERVIEW INFORMATION SHEET

Insert Researcher Picture	My name is XResearcher NameX
	I am a researcher.
 	I want to find out about your experience of the memory group using a Talking Mat. I would like to ask you questions about What you liked What you feel unsure about What you did not like This will let us know if it is a helpful group for people.

	I will record our conversation and take a picture of the Talking Mat This is to help me remember what you have said and to help me write a report.
   1234	I will keep the recording, picture and all information about you safe and secure. Although if you say anything to us which puts you or anyone else in danger, we may need to report this to the right person to help. We will write our reports in a way that no-one can work out that you took part in the study. I will not use your name and address when writing reports or looking at results. Your information will have an ID number instead.

  	You can tell me Yes if you want to still talk with me You can tell me No if you do not want to still talk with me If you say No it will not change the care you get You can stop taking part at any time
	Do you have any questions for me?
	Do you want to take part?

Appendix E: Information Sheet for carers



CARER QUALITATIVE INTERVIEW INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Information sheet for personal/family/relative carers

Introduction

Your relative/friend has been taking part in our study for Cognitive Stimulation Therapy (CST) for people with a learning disability and dementia. There is evidence that group CST is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. During this study we would like to find out if the manual and activities that we have proposed are enjoyable and are easy to follow and whether we can carry out another bigger study.

In order to help us plan a future study we would like your opinion on how you and your relative/ friend found the research process. If your relative/ friend attended some or all of the groups, we would also like your opinion on how your friend or relative experienced the groups they attended as part of this study. **What will happen if I agree to the interview?**

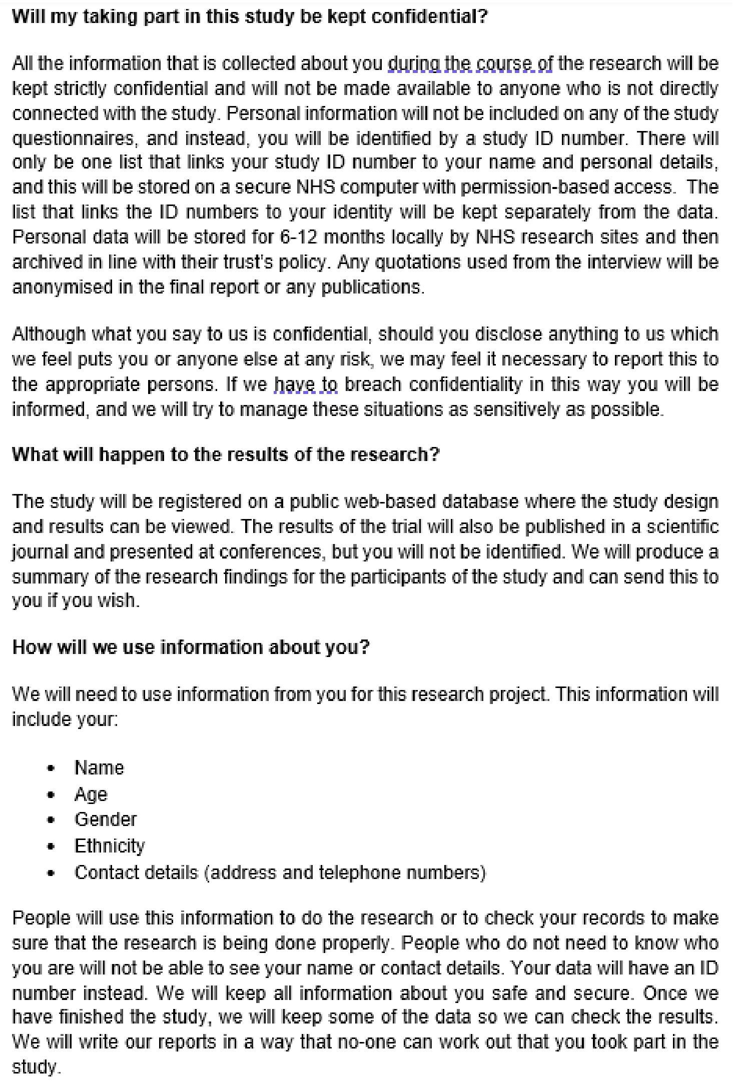
If you agree, you will be invited to take part in an interview about the research process and the group, if your friend or relative attended them. The interview will take about 30-60 minutes and can take place face to face, over video call or on the telephone. We will audiotape and transcribe the interview. We will remove any information that could identify you from the transcripts and the recording will be deleted from the digital recorder. The information we receive about the groups will help us to check whether the groups were adequately adapted for your friend or relative and if it was enjoyed and affected them in their day-to-day life. The information you give will also help us to know if running a large study evaluating the effects of CST is feasible.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for you in taking part. However, by taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.



Will my taking part in this study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Personal information will not be included on any of the study questionnaires, and instead, you will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be stored on a secure NHS computer with permission-based access. The list that links the ID numbers to your identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any quotations used from the interview will be anonymised in the final report or any publications.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed, and we will try to manage these situations as sensitively as possible.

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have an ID number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Name and Name who are Chief Investigators of the research project. The study is being sponsored by Trust Name

London NHS Foundation Trust. The study is funded by the National Institute of and Care Health Research (Award ID: NIHR201934). The National Institute of and Care Health Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by the Health Research Authority and has also been given favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/02/47).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigator (see details below) who will do her best to address the issues. You can also contact the Patient Advice and Liaison Service (PALS) for independent advice (see below). They can give you information about how you can complain formally through the NHS Complaints Procedure. You can also obtain details from your local NHS Trust.

In the event that something goes wrong, and you are harmed during the research, and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.

Local PALS telephone number: Insert local PALS contact number
Local PALS email: Insert local PALS email address

Contact for researcher (name, address, email)

Contact details for local research team (name, address, telephone and email)

Principal Investigator contact details (name, address, telephone and email)

Contact details for Chief Investigators (name, address, telephone and email)

Appendix F: Information Sheet for facilitators

FACILITATOR QUALITATIVE INTERVIEW INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction

There is evidence that Group Cognitive Stimulation Therapy (CST) is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. We would like to find out if the manual and activities that we have proposed are feasible and acceptable.

We would like your opinion on how participants experienced the groups they attended as part of this study and your experience of running the groups. The information you give us will help us to check whether the groups were adequately adapted for the participants and if it was enjoyed and affected them in their day-to-day life. It will also help us to know if running a large study evaluating the effects of CST is feasible.

What will happen if I agree to the interview?

If you agree you will be invited to take part in an interview. The interview will take about 30-60 minutes and can take place face to face, on the telephone or video call. We will audiotape and transcribe the interview. We will remove any information that could identify you, the group participants or carers from the transcripts and the recording will be deleted from the digital recorder.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for you in taking part. However, by taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.

Will my taking part in this study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Your information will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be stored on a secure NHS computer with permission-based access. The list that links the ID numbers to your identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any quotations used from the interview will be anonymised in the final report or any publications.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed, and we will try to manage these situations as sensitively as possible.

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

How will we use information about you?

We will need to use information from you for this research project. This information will include your

- Name
- Age
- Gender
- Ethnicity
- Contact details (work address and telephone number, as well as email address if video call)
- Occupation

People who do not need to know who you are will not be able to see your name or contact details. Your data will have an ID number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Name and Name who are the Chief Investigators of the research project. The study is being sponsored by Trust Name NHS Foundation Trust. It is funded by the National Institute of Health and Care Research (Award ID: NIHR201934). The National Institute of Health and Care Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by the Health Research Authority and has also been given favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/02/47).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to the researcher conducting these interviews or your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigators (see details below) who will do her best to address the issues. You can also follow your local procedure in your NHS Trust to raise a concern or make a complaint.

In the event that something goes wrong, and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.
Local PALS telephone number: Insert local PALS contact number
Local PALS email: Insert local PALS email address

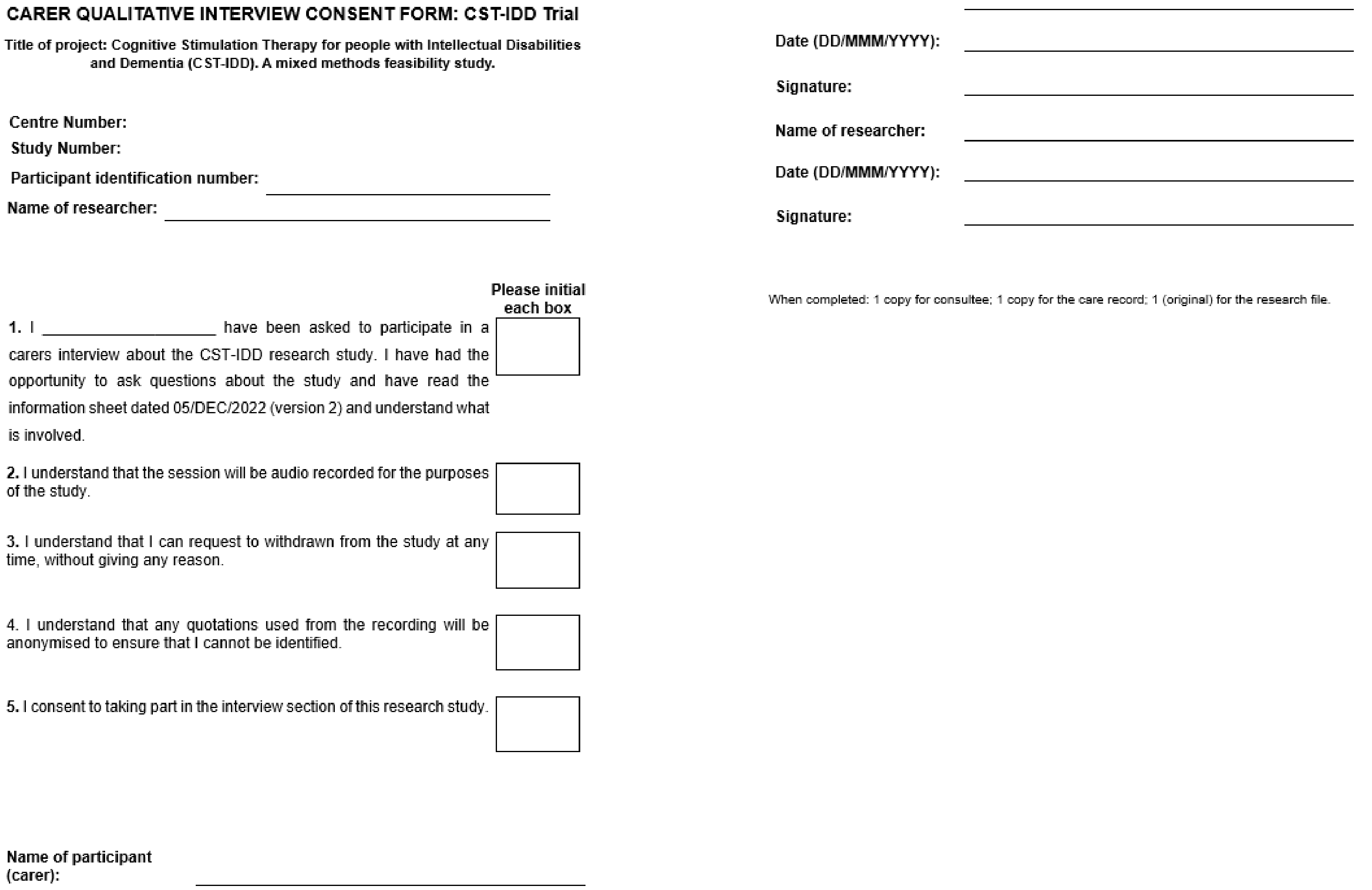
Contact for researcher (name, address, email)

Contact details for local research team (name, address, telephone and email)

Principal Investigator contact details (name, address, telephone and email)

Contact details for Chief Investigators (name, address, telephone and email)

Appendix G: Consent Form for carers



CARER QUALITATIVE INTERVIEW CONSENT FORM: CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Centre Number:
Study Number:
Participant identification number: ____________________
Name of researcher: ____________________

Please initial each box

1. I ____________ have been asked to participate in a carers interview about the CST-IDD research study. I have had the opportunity to ask questions about the study and have read the information sheet dated 05/DEC/2022 (version 2) and understand what is involved. ☐

2. I understand that the session will be audio recorded for the purposes of the study. ☐

3. I understand that I can request to withdrawn from the study at any time, without giving any reason. ☐

4. I understand that any quotations used from the recording will be anonymised to ensure that I cannot be identified. ☐

5. I consent to taking part in the interview section of this research study. ☐

Name of participant (carer): ____________________

____
Date (DD/MMM/YYYY): ____________________
Signature: ____________________
Name of researcher: ____________________
Date (DD/MMM/YYYY): ____________________
Signature: ____________________

When completed: 1 copy for consultee; 1 copy for the care record; 1 (original) for the research file.

Appendix H: Consent Form for facilitators

FACILITATOR QUALITATIVE INTERVIEW CONSENT FORM:
CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Centre Number:
Study Number: 306756
Participant (facilitator) identification number: _______________

Name of researcher: ___________________________

Please initial each box:

1. I ________________________have been asked to participate in a facilitator interview about the group(s) I have been facilitating in this research study. I have had the opportunity to ask questions about the study and have read the information sheet dated ____/____/______ (version_____) and understand what is involved. ☐

2. I understand that the session will be audio recorded for the purposes of the study. ☐

3. I understand that I can request to withdrawn from the study at any time, without giving any reason. ☐

4. I understand that any quotations used from the recording will be anonymised to ensure that I cannot be identified. ☐

5. I consent to taking part in the interview section of this research study. ☐

Name of participant (facilitator): _____________________________

Date (DD/MMM/YYYY): _____________________________________

Signature: ____

Name of researcher: _____________________________

Date (DD/MMM/YYYY): _____________________________________

Signature: ____

When completed: 1 copy for facilitator; 1 (original) for the research file.

Appendix I: Interview Schedules for people with ID&D (group participants)

Group participant interview schedule

Group A:

Group name:

Song:

Carers involvement in the group:

Session interviewing after:

Interview

Go through information sheet

Introduce the mat: Today we are talking about the ________________ group (card on bottom of mat)

I would like to hear about what you liked about the _______________group (card top left)

What you did not like about the _______________ group (card top right)

And things that you are unsure about in relation to the _____________group (card top middle)

I will give you a picture one at a time. You can decide where to put it.

If it was something you liked put it here (left), if it was something you did not like put it here (right), and if it was something you are unsure about put it in the middle.

How did you feel about…..

- The group quiz/ ______________that you did today in the _________ group?
- The other activities that you have done in the _________ group?
- Being in a group setting?
- The support you got from ___________ and _________ the group leaders?
- Your carer ___________ being/not being in the _________ group?
- The ________ group sessions were ______ long. How did you feel about the length of the _________ group sessions?

If it is something you use when eating food you put it here (left), if it is something you do not use when eating food you put it here (right), and if it is something you are unsure about put it in the middle.

Do you use __________ for eating food?

- A fork?
- Bowls?
- A football?
- A cup?
- A spoon?

Check: start with negative to positive

- So these were the things you use for eating food
- These are in the middle
- These things you do not use for eating food

Change: Is there anything you would like to change?

- How did you feel about going to the _________ group twice a week?
- Having breaks half way through the _________ group sessions?
- Talking about your experiences and ideas in the _________ group?
- Hearing about other people's experiences and ideas in the _________ group?

Anything missed: Is there anything else that we have missed that you would like to say about the _________ group? (offer blank cards)

Check: start with negative to positive

So these were the things you did not like

These are in the middle

These things you did like about the group

Change: Is there anything you would like to change?

Follow up questions as go along or during review:

What did you like/not like about _________?

In what way would you have liked _________ to be different?

Ending: Thank you for your time and comments

Would you like a copy of the talking mat picture to look back on?

Any final questions?

Validation exercise

Introduce the mat: Now we are talking about things we use for eating food (card on bottom of mat)

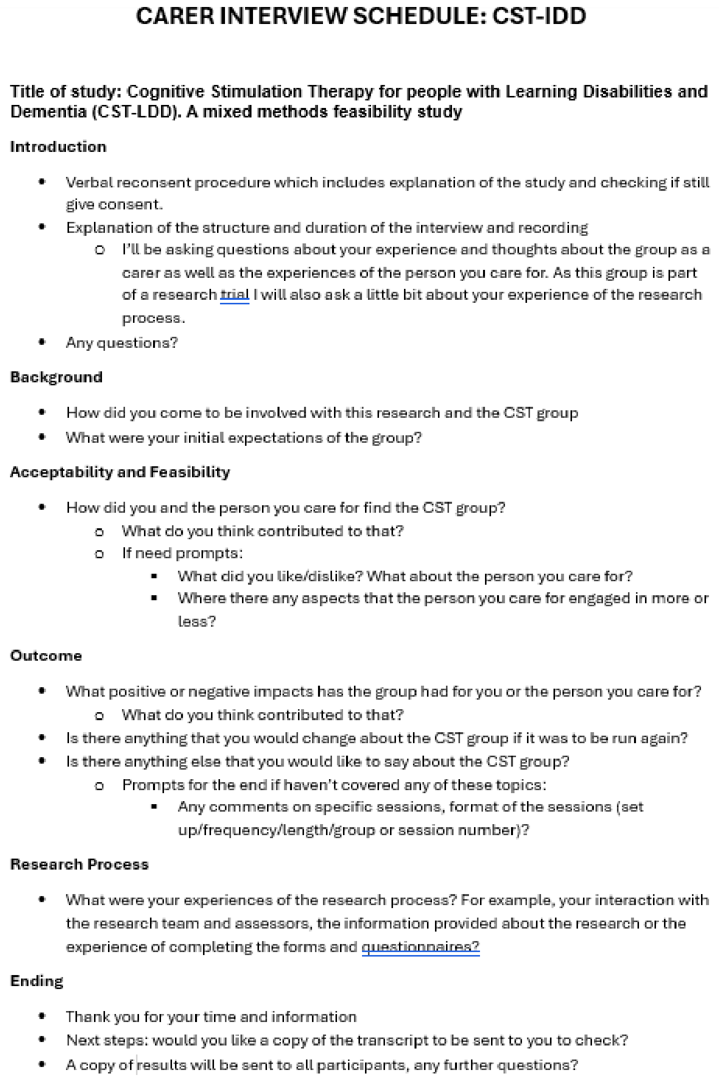
I would like you to tell me what is good to use when eating food (card top left)

What is not good to use when eating food (card top right)

And things that you are unsure about in relation to eating food (card top middle)

I will give you a picture one at a time. You can decide where to put it.

Appendix J: Interview Schedules for carers



CARER INTERVIEW SCHEDULE: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-LDD). A mixed methods feasibility study

Introduction

- Verbal reconsent procedure which includes explanation of the study and checking if still give consent.
- Explanation of the structure and duration of the interview and recording
    - I'll be asking questions about your experience and thoughts about the group as a carer as well as the experiences of the person you care for. As this group is part of a research trial I will also ask a little bit about your experience of the research process.
- Any questions?

Background

- How did you come to be involved with this research and the CST group
- What were your initial expectations of the group?

Acceptability and Feasibility

- How did you and the person you care for find the CST group?
    - What do you think contributed to that?
    - If need prompts:
        - What did you like/dislike? What about the person you care for?
        - Where there any aspects that the person you care for engaged in more or less?

Outcome

- What positive or negative impacts has the group had for you or the person you care for?
    - What do you think contributed to that?
- Is there anything that you would change about the CST group if it was to be run again?
- Is there anything else that you would like to say about the CST group?
    - Prompts for the end if haven't covered any of these topics:
        - Any comments on specific sessions, format of the sessions (set up/frequency/length/group or session number)?

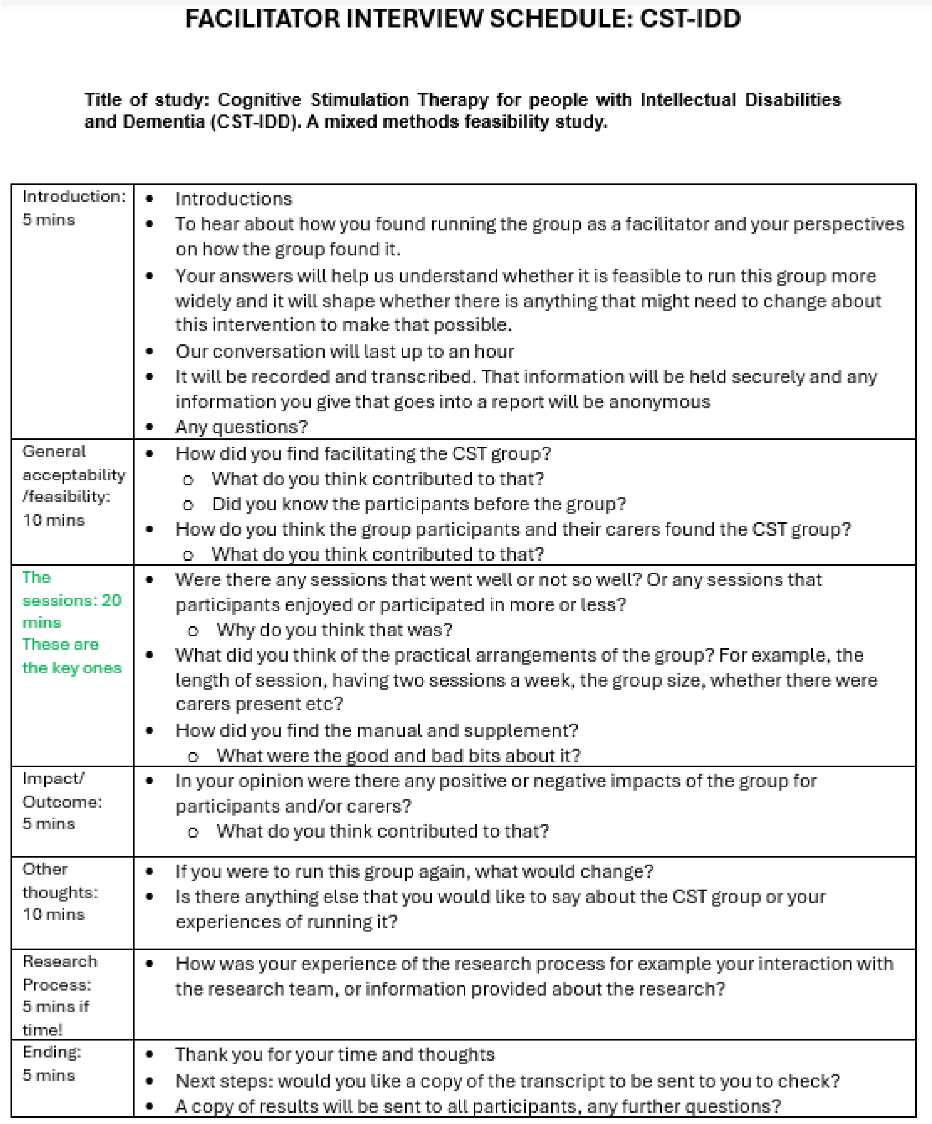
Research Process

- What were your experiences of the research process? For example, your interaction with the research team and assessors, the information provided about the research or the experience of completing the forms and questionnaires?

Ending

- Thank you for your time and information
- Next steps: would you like a copy of the transcript to be sent to you to check?
- A copy of results will be sent to all participants, any further questions?

Appendix K: Interview Schedules for facilitators

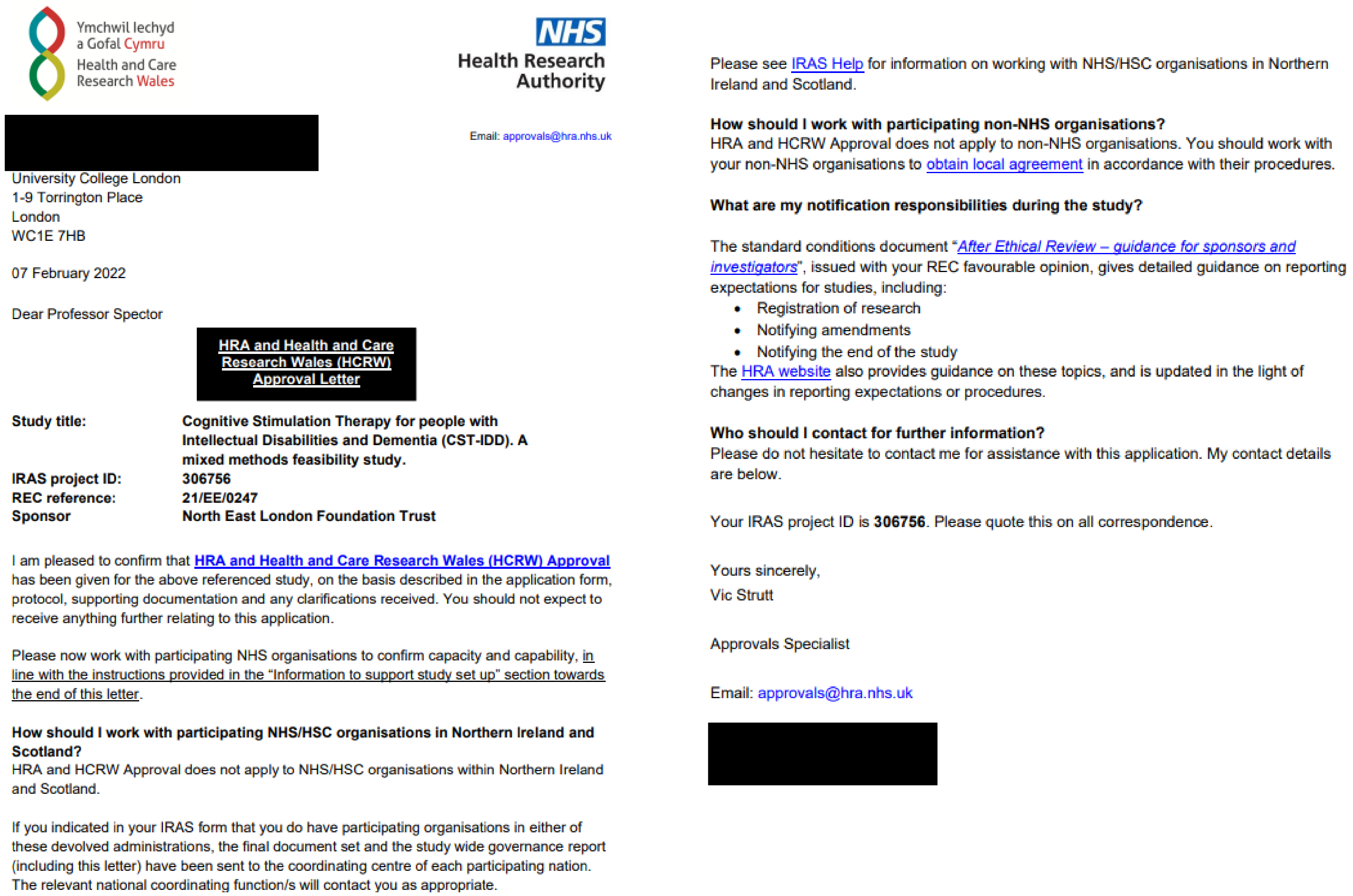


FACILITATOR INTERVIEW SCHEDULE: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction: 5 mins	• Introductions • To hear about how you found running the group as a facilitator and your perspectives on how the group found it. • Your answers will help us understand whether it is feasible to run this group more widely and it will shape whether there is anything that might need to change about this intervention to make that possible. • Our conversation will last up to an hour • It will be recorded and transcribed. That information will be held securely and any information you give that goes into a report will be anonymous • Any questions?
General acceptability /feasibility: 10 mins	• How did you find facilitating the CST group? o What do you think contributed to that? o Did you know the participants before the group? • How do you think the group participants and their carers found the CST group? o What do you think contributed to that?
The sessions: 20 mins These are the key ones	• Were there any sessions that went well or not so well? Or any sessions that participants enjoyed or participated in more or less? o Why do you think that was? • What did you think of the practical arrangements of the group? For example, the length of session, having two sessions a week, the group size, whether there were carers present etc? • How did you find the manual and supplement? o What were the good and bad bits about it?
Impact/ Outcome: 5 mins	• In your opinion were there any positive or negative impacts of the group for participants and/or carers? o What do you think contributed to that?
Other thoughts: 10 mins	• If you were to run this group again, what would change? • Is there anything else that you would like to say about the CST group or your experiences of running it?
Research Process: 5 mins if time!	• How was your experience of the research process for example your interaction with the research team, or information provided about the research?
Ending: 5 mins	• Thank you for your time and thoughts • Next steps: would you like a copy of the transcript to be sent to you to check? • A copy of results will be sent to all participants, any further questions?

Appendix L: Health Research Authority ethical approval letter



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: approvals@hra.nhs.uk

[redacted]
University College London
1-9 Torrington Place
London
WC1E 7HB

07 February 2022

Dear Professor Spector

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.**
IRAS project ID:	**306756**
REC reference:	**21/EE/0247**
Sponsor	**North East London Foundation Trust**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

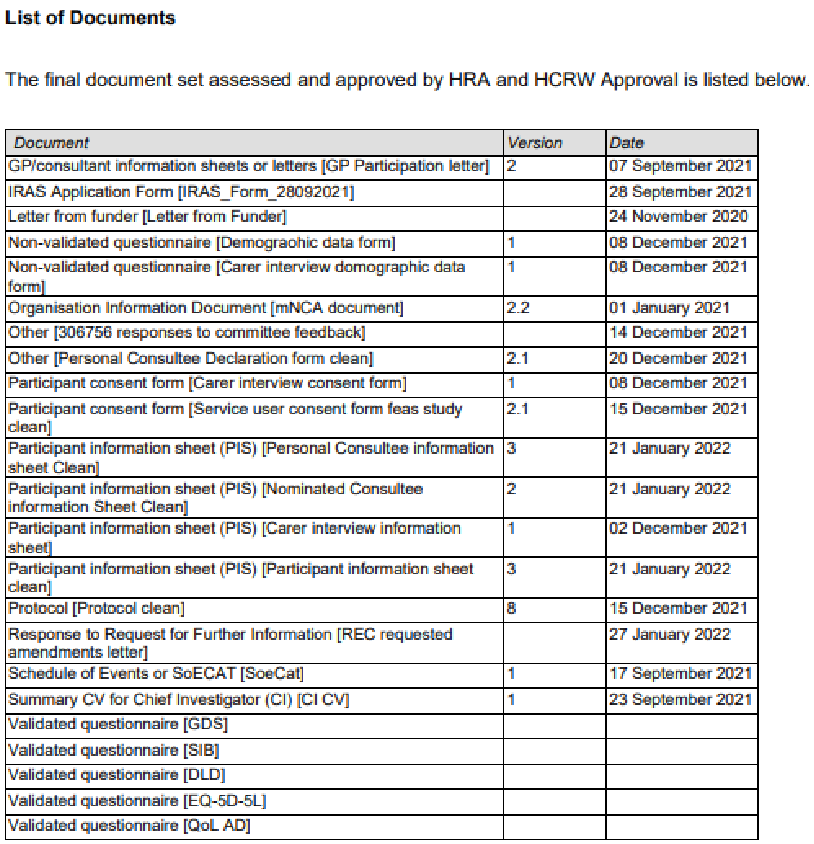
Your IRAS project ID is **306756**. Please quote this on all correspondence.

Yours sincerely,
Vic Strutt

Approvals Specialist

Email: approvals@hra.nhs.uk

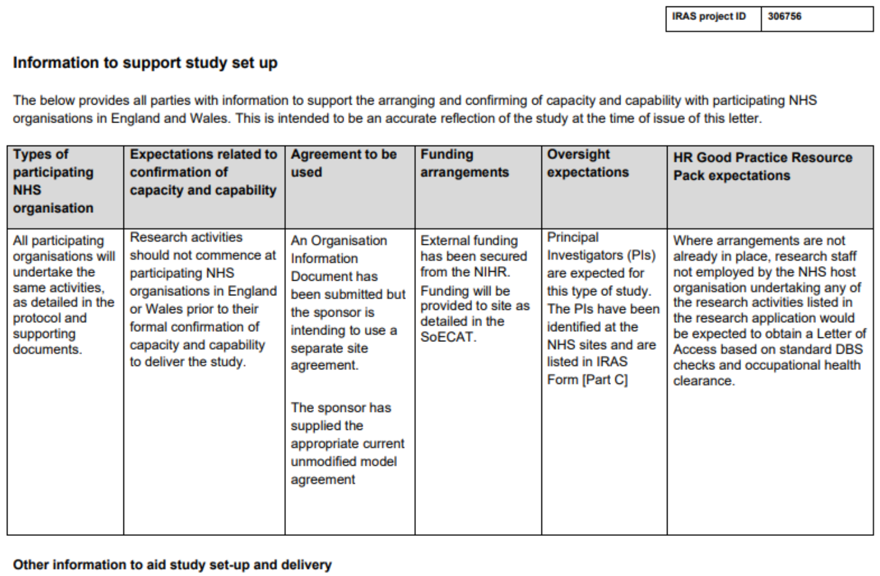
[redacted]



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
GP/consultant information sheets or letters [GP Participation letter]	2	07 September 2021
IRAS Application Form [IRAS_Form_28092021]		28 September 2021
Letter from funder [Letter from Funder]		24 November 2020
Non-validated questionnaire [Demograohic data form]	1	08 December 2021
Non-validated questionnaire [Carer interview domographic data form]	1	08 December 2021
Organisation Information Document [mNCA document]	2.2	01 January 2021
Other [306756 responses to committee feedback]		14 December 2021
Other [Personal Consultee Declaration form clean]	2.1	20 December 2021
Participant consent form [Carer interview consent form]	1	08 December 2021
Participant consent form [Service user consent form feas study clean]	2.1	15 December 2021
Participant information sheet (PIS) [Personal Consultee information sheet Clean]	3	21 January 2022
Participant information sheet (PIS) [Nominated Consultee information Sheet Clean]	2	21 January 2022
Participant information sheet (PIS) [Carer interview information sheet]	1	02 December 2021
Participant information sheet (PIS) [Participant information sheet clean]	3	21 January 2022
Protocol [Protocol clean]	8	15 December 2021
Response to Request for Further Information [REC requested amendments letter]		27 January 2022
Schedule of Events or SoECAT [SoeCat]	1	17 September 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	23 September 2021
Validated questionnaire [GDS]		
Validated questionnaire [SIB]		
Validated questionnaire [DLD]		
Validated questionnaire [EQ-5D-5L]		
Validated questionnaire [QoL AD]		



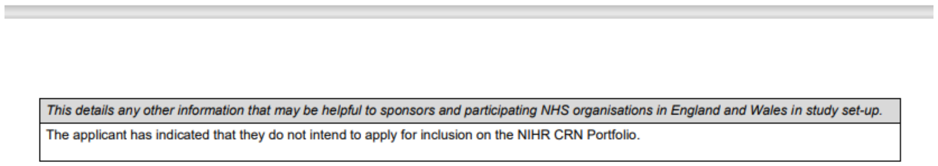
IRAS project ID	**306756**

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
All participating organisations will undertake the same activities, as detailed in the protocol and supporting documents.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted but the sponsor is intending to use a separate site agreement. The sponsor has supplied the appropriate current unmodified model agreement	External funding has been secured from the NIHR. Funding will be provided to site as detailed in the SoECAT.	Principal Investigators (PIs) are expected for this type of study. The PIs have been identified at the NHS sites and are listed in IRAS Form [Part C]	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery



This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix M: Outline of contributions to part 2

Outline of joint project contributions with previous Trainee Psychologist Joanna Carter and with support from members of the CST-IDD acceptability and feasibility trial. Outline of additional contributions to the CST-IDD trial.

Part two contributions

Joint project with DClin Psy trainee Joanna Carter

1) Research proposal: Joanna Carter

My research proposal stated an initial plan to support with and write up the quantitative findings for the wider CST-IDD trial. Joanna's project planned to write up the qualitative findings. Due to recruitment difficulties Joanna was unable to complete the qualitative project before her thesis deadline and I took on the qualitative project as this was most useful for the CST-IDD trial team.

2) Development of interview schedules: Joanna Carter

I intended to write up the quantitative findings at this stage.

3) Four qualitative interviews within the first NHS site: three by Joanna Carter and one by Cheryl Francis

Three were completed by Joanna as part of the initial plan for Joanna to write up the qualitative findings. I completed one facilitator interview to support Joanna with qualitative data collection.

4) 16 qualitative interviews: Cheryl Francis

Following the confirmed change to a qualitative project, I carried out all remaining interviews across three NHS sites.

5) Transcribing participant (people with ID&D) interviews: Cheryl Francis

As these interviews did not have a Microsoft Teams auto transcript, I transcribed these interviews using voice recordings and my notes from the session.

6) Qualitative analysis and write up: Cheryl Francis

Support from members of the CST-IDD acceptability and feasibility trial

7) Information sheets, consent forms and ethical approval: various members of the CST-IDD trial

Developed by various members of the CST-IDD trial prior to my joining the project.

8) Cleaning up and formatting 11 transcripts: Sarah Hoare (Research Assistant, CST-IDD trial)

Support from Sarah in formatting 11 Microsoft Teams auto transcripts.

9) Support with securely storing all information (e.g. video recordings for facilitator and carer interviews, transcripts, consent forms): Sarah Hoare (Research Assistant, CST-IDD trial) and Cheryl Francis

I sent all identifiable non-anonymised data (video recordings, transcripts, consent forms) from an encrypted USB via NHS egress for secure transfer. Sarah stored all data within the relevant locations for the main CST-IDD trial.

10) Collecting retrospective signed consent forms from carers and facilitators (and protocol violation forms): Sarah Hoare (Research Assistant, CST-IDD trial) and two collected by Cheryl Francis.

I supported with the process of collecting two retrospective signed consent forms (and completing the associated protocol violation forms) for carers and facilitator qualitative interviews.

Remaining retrospective consent forms (and completing the associated protocol violation forms) were completed by Sarah.

Other CST-IDD trial contributions

11) Completed one follow up assessment and scoring within the first NHS site (Severe Impairment Battery, Dementia Questionnaire for people with Learning Disabilities, EQ-5D-5L quality of life questionnaire proxy and participant version): Cheryl Francis

Completed with the initial plan to write up the quantitative findings and oversee baseline and follow up assessments across five NHS sites. Did not continue with this plan due to the switch from a quantitative to qualitative project.

12) Development of additional interview schedules – Cheryl Francis

Developed additional interview schedules for carers and facilitators & service managers for groups that struggled to recruit or where participants did not consistently attend groups.

Interim plan to complete this piece of work alongside the quantitative write up.

As I took on the main qualitative write up, these did not go ahead and were not part of the original CST-IDD protocol (although had been submitted as part of an ethics amendment). Additionally, when assessing interest in participation, facilitators for groups that did not go ahead did not seem keen to participate due to significant difficulties with the setting up processes.